DOCUMENT RESUME

ED 348 814 EC 301 435

AUTHOR	Schmitt, Christopher, Ed.
TITLE	Parent Resource Directory. Fourth Edition.
INSTITUTION	Association for the Care of Children's Health, Bethesda, MD.
SPONS AGENCY	Health Resources and Services Administration (DHHS/PHS), Rockville, MD. Office for Maternal and Child Health Services.
REPORT NO	ISBN-0-937821-76-4
PUB DATE	May 91
CONTRACT	MCJ-115039
NOTE	129p.
PUB TYPE	Reference Materials - Directories/Catalogs (132)
EDRS PRICE	MF01/PC06 Plus Postage.
DESCRIPTORS	*Disabilities; Foreign Countries; Health Services; *Information Networks; *Information Services; Parent Associations; Parent Education; *Social Support Groups; *Special Health Problems
IDENTIFIERS	Canada; United States

ABSTRACT

This directory was produced to help parents of children with special needs and professionals identify one another and form relationships to improve the health care system. The directory contains entries from families throughout the United States and Canada, and is organized alphabetically by state or province, with parents listed alphabetically within each area. Each entry contains such information as the parent name, address, telephone, child's or children's disabilities, organizational affiliations of the parent, care facility used, skills and interests of the parent, experience, related employment, and languages other than English. At the end of the directory are a general alphabetical index of parents, an index of disabilities, and an index of special interests. There is also a list of Parent Training and Information Centers, which are federally funded programs, staffed by parents, that provide information to parents on special education laws. (JDD)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)
☑ This document has been reproduced as received from the person or organization originating it.
☐ Minor changes have been made to improve reproduction quality.
• Points of view or opinions stated in this document do not necessarily represent official OERI position or policy.

ED 403 814

Parent Resource Directory

Fourth Edition

Christopher Schmitt, Editor

EC 301435

BEST COPY AVAILABLE

Association for the
Care of Children's Health

With support from the Maternal and Child Health Bureau

This publication was developed by the National Center for Family-Centered Care, a program of the Association for the Care of Children's Health (ACCH), with support from the Maternal and Child Health Bureau, Health Resources and Services Administration, U.S. Department of Health and Human Services, through grant #MCJ-115039.

The National Center for Family-Centered Care promotes the practice of family-centered care for children with special health care needs and their families; fosters parent/professional collaboration at all levels of health care; and supports research and evaluation efforts to document the effectiveness of family-centered approaches to care.

ACCH is devoted to improving the ways in which the health care community responds to the unique emotional and developmental needs of children. Founded in 1965, ACCH brings together in partnerships professionals from a variety of disciplines and families to improve health care and support services for children and families. Through advocacy, educational programs, and publications and other media, ACCH works to make a difference for children and families in health care environments.

For more information, contact:

ACCH
7910 Woodmont Avenue, Suite 300
Bethesda, MD 20814
301 654-6549

Parent Resource Directory

Fourth Edition
May 1991

Christopher Schmitt, Editor

Association for the Care of Children's Health
Bethesda, Maryland

Copyright 1991, Association for the Care of Children's Health
7910 Woodmont Avenue, Suite 300
Bethesda, Maryland 20814

Fourth Edition, First Printing

ISBN 0-937821-76-4

Table of Contents

Introduction 1

Organization of the Directory 2

Parent Listings

United States

Alabama 3
Alaska 5
Arizona 6
Arkansas 7
California 8
Colorado 14
Connecticut 14
Delaware 16
District of Columbia 16
Florida 17
Georgia 21
Hawaii 21
Idaho 25
Illinois 26
Indiana 27
Iowa 30
Kansas 33
Kentucky 34
Louisiana 35
Maine 38
Maryland 39
Massachusetts 42
Michigan 44
Minnesota 48
Mississippi 51
Missouri 52
Montana 53
Nebraska 53
Nevada 54
New Hampshire 55
New Jersey 56
New Mexico 58
New York 62
North Carolina 65
North Dakota 67

Table of Contents

Ohio 68
Oklahoma 71
Oregon 73
Pennsylvania 74
Rhode Island 77
South Carolina 77
South Dakota 78
Tennessee 79
Texas 80
Utah 86
Vermont 87
Virgin Islands 91
Virginia 91
Washington 93
West Virginia 94
Wisconsin 95
Wyoming 97

Canada

British Columbia 98
New Brunswick 98
New Foundland 98
Nova Scotia 99
Ontario 99

Index of Names 101

Index of Disabilities 107

Index of Special Interests 113

Parent Training and Information Centers (PTIs) 115

Directory Information Form 119

Directory Evaluation Form 121

Introduction

Family-centered care is a philosophy of care that recognizes the central role of the family in a child's life. Family-centered care supports families in their caregiving roles by building on their unique strengths as families and on the strengths of individual family members. Two important elements of family-centered care that bring this philosophy to life are parent/professional collaboration and family-to-family support and networking.

Partnerships between parents and professionals in all aspects of health care are an essential ingredient of family-centered care. This directory was produced, in part, to help parents and professionals identify one another and form relationships to improve the health care system for children with special needs and their families. ACCH holds that parents should at all times be compensated for their service. If payment is not possible, at a very minimum, child care, travel, meals, and accommodations should be covered. All such arrangements should be agreed upon in advance.

Family networking is a valued tool that not only provides support for family members, but also helps to improve the ways in which children with special needs and their families are cared for. ACCH hopes the directory will help parents locate others who share their interests, concerns, and experiences.

This is the fourth edition of the *Parent Resource Directory*. It has proven in the past to be a valuable resource for parents and professionals alike. For example, it has been used both locally and nationally by parents seeking support from one another, by service providers seeking to link parents together, and by both parents and professionals seeking to influence legislation or hospital policy. ACCH is committed to furthering this process and will continue to maintain a database of parent listings. You can help by sharing the information form in the back of this directory with other families who care for children with special needs. This form should also be used to make corrections or changes in current listings.

Organization of the Directory

The directory contains entries from families throughout the United States and Canada. It is organized alphabetically by state or province, with parents listed alphabetically within each area. Some areas include little or no parent listings. This is not a reflection of the level of parent involvement in a region, but rather the ways in which parents have become known to ACCH – through conferences, newsletters, and other networking activities. In addition, at the end of the directory, there is a general alphabetical index of parents, an index of disabilities, and an index of special interests (relating to entries under "Skills and Interests," "Experience," and "Languages other than English"). There is also a list of Parent Training and Information Centers (PTIs). PTIs are federally funded programs, staffed by parents, to provide information to parents on the special education laws and are designated by an asterisk (*) in the parent listings. The following information is presented in the listings:

Parent Name
Address
Telephone (when two numbers are given, the first is the daytime phone)
Child's or children's disabilities (and birthdate if provided)
Affiliations
Care facility (where child receives majority of care)
Skills and Interests
Experience
Related Employment
Languages other than English

When categories of information are not applicable or were not provided by the parent, they are omitted.

9

United States

ALABAMA

Chris and Sharon Albright
4505 Grizzard Road
Huntsville, AL 35810

Child's Disabilities: Extreme hydrocephalus; Arnold-Chiari malformation II; spina bifida
Affiliations: Comprehensive Early Intervention Services; Parent Partners in Policy Making -- Executive Committee; Spina Bifida Group of Huntsville; HRP Support Group; ARC
Care Facility: The Children's Hospital -- Birmingham, AL
Skills and Interests: Early intervention; group home living; sibling issues; parent networking
Experience: Promoting legislation (especially P.L. 99-457); starting or maintaining parent/family support groups; public speaking; training parents
Related Employment: Advocate

Charlotte Bell
2107 Chestnut Road
Birmingham, AL 35216
205 822-2589

Child's Disabilities: Down syndrome (02/14/84)
Affiliations: Parent Advocates/Down Syndrome -- Board Member; ARC -- Board Member; Jefferson County Consortium; Parent Advisory Committee -- Vestavia Hills, AL; Children's Hospital -- Volunteer, Down Syndrome Clinic
Care Facility: Greenville Pediatrics and Down Syndrome Clinic, Children's Hospital -- Birmingham, AL
Skills and Interests: Addressing education needs through conferences
Experience: Starting or maintaining parent/family support groups; public speaking; training parents, health care providers, or teachers

Carol R. Blades
P.O. Box 161274
Mobile, AL 36616-2274
205 478-1208
205 633-9588

Child's Disabilities: Deafness; multiple handicaps
Affiliations: VOA -- Center for Hearing Impaired; ARC; Council for Exceptional Children; Parents of Alabama Center for Training -- Director; *Special Education Action Committee
Care Facility: Mobile Infirmary -- Mobile, AL
Experience: Public speaking; conducting training sessions for health care providers/teachers; promoting legislation; starting or maintaining support groups
Related Employment: Teacher and parent trainer, *Special Education Action Committee

Susan Colburn
2516 McGraw Court
Montgomery, AL 36116

Children's Disabilities: Spina bifida; hydrocephalus (03/31/86); Prematurity (23 week gestation) (07/23/89)
Affiliations: Friends for Life -- Co-coordinator; Spina Bifida Association of Alabama
Care Facility: The Children's Hospital -- Birmingham, AL
Experience: State ICC -- Parent Representative; Alabama Special Education Advisory Panel -- Parent Representative; Coordinating Handicapped Infant and Preschool Services Council; starting or maintaining parent/family support groups; public speaking; training parents; promoting legislation

Ann Cosby
600-C Maxwell Boulevard
Maxwell AFB, AL 36113

Child's Disabilities: Neurological damage (12/15/86)
Affiliations: Friends for Life; March of Dimes; Coordinating Handicapped Infant & Preschool Services Council -- Co-chairwoman
Care Facility: Air University Regional Hospital -- Maxwell AFB, AL
Experience: Starting or maintaining parent/family support groups; public speaking; promoting legislation

Louise Hoffman
5301 Tenth Avenue, S.
Birmingham, AL 35222

Child's Disabilities: Down syndrome (12/70)
Affiliations: Parent Advocates/Down Syndrome (PADS) -- Board Member, Group Home

Committee Member
Care Facility: Birmingham Pediatrics
Skills and Interests: Vocational training

Brenda Holmes-King
P.O. Box 480204
Linden, AL 36748
205 295-8013
205 289-9125

Child's Disabilities: Rubella syndrome (12/03/64)
Affiliations: Alabama Deaf Blind Multihandicapped Association; ARC; Helen Keller National Center -- National Parent Network; National Association for Parents of the Visually Impaired
Care Facility: The Children's Hospital, The Eye Foundation, and Child Development Learning Disorders -- Birmingham, AL
Skills and Interests: Respite care; recreation therapy; advocacy; transition; stress/relaxation and therapy/coping skills
Experience: PRO of New Mexico; Alabama Deaf Blind Task Force; Alabama State Department of Special Education; starting or maintaining parent/family support groups; training parents and teachers; public speaking; promoting legislation
Related Employment: Project Coordinator, Consumer Survey of Assessments for Information and Referral Services for Partially Sighted Individuals, Rehabilitation Research and Training Center, Mississippi State University

Faye Johnson
12 Arden Road
Montgomery, AL 36109
205 277-3270

Child's Disabilities: Noonan's syndrome; hypertrophic cardiomyopathy; epilepsy (11/07/67)
Affiliations: Friends Forever; Frazier Memorial Methodist
Care Facility: Air University Regional Hospital -- Maxwell AFB, AL

Bruce and Diana Koppenhoefer
2761 Crestview Avenue
Montgomery, AL 36109
205 271-5263

Child's Disabilities: Mental retardation; seizure disorder (12/06/81)
Affiliations: Friends for Life/Montgomery -- Hospitality Chairman; ARC/Alabama; March of Dimes
Care Facility: Baptist Hospital -- Montgomery, AL
Skills and Interests: Respite care
Experience: Supporting legislation; starting or maintaining parent/family support groups

Kathy Neno
9261 Ponderosa Drive, S.
Semmes, AL 36575
205 470-1693
205 649-8460

Child's Disabilities: Hyaline membrane disease; persistent fetal circulation (02/06/83)
Affiliations: Parent Care, Inc.; Parents of Miracles -- Founder and Coordinator
Care Facility: Private physician -- Mobile, AL
Skills and Interests: Early intervention
Experience: Local Interagency Coordinating Council for 99-457; coordinating and teaching parent listening sessions; starting or maintaining parent/family support groups; public speaking; training parents, health care providers, or teachers
Related Employment: Parent Support Coordinator and NICU Staff Nurse, University of South Alabama Medical Center

Michael D. and Elizabeth D. Prince
7530 Halcyon Forest Trail
Montgomery, AL 36117

Child's Disabilities: Developmental delays; seizure disorder; vision deficits
Affiliations: Frazer's Friends for Life -- Co-chairman, Support & Service Group for Families of Special Needs Children; CHIPS (local Planning Council for Coordinating Handicapped Infant and Preschool Services) -- Co-chairman, Family Support Committee; Partners in Policymaking of Alabama
Care Facility: Private physician; Baptist Hospital -- Montgomery, AL
Skills and Interests: Funding issues; day care options for children with disabilities; respite care; training; family involvement and public awareness in implementation of P.L. 99-457
Experience: Starting or maintaining parent/family support groups; public speaking; training parents and individuals with disabilities; promoting legislation

Lynn Terry
2445 Wine Ridge Drive
Birmingham, AL 35244

Child's Disabilities: Developmental delay (08/10/88)
Care Facility: ARC Hope Program -- Birmingham, AL
Skills and Interests: Educational needs; day care; developing a Birmingham chapter of Friends for Life
Experience: Starting or maintaining parent/family support groups; public speaking; training parents, health care providers, or teachers
Related Employment: R.N., in NICU

Gwen and Albert Wasden
P.O. Box 8155
Montgomery, AL 36110

Child's Disabilities: Herpes Simplex II; blindness; seizures; brain damage; diabetes; incepitis (06/27/89)
Affiliations: Friends for Life; HOPE Project; PIP Program
Care Facility: Children's Hospital -- Birmingham, AL

ALASKA

Beth Edmands
344 East 15th Street, #2
Anchorage, AK 99501
907 277-4922

Child's Disabilities: Down syndrome
Affiliations: Advocacy Services of Alaska (ASK) -- President
Care Facility: Private physician
Skills and Interests: Special education; integration; child care; training health and education professionals about the needs of children with disabilities and their families
Experience: Public speaking; conducting training sessions for health care providers and/or teachers; promoting legislation; starting or maintaining parent/family support groups
Related Employment: Associate Executive Director, Anchorage Community YMCA

Kayleen C. Lowe
P.O. Box 91977
Anchorage, AK 99509-1977
907 248-4195

Child's Disabilities: Bronchopulmonary dysplasia; profound developmental delay (07/14/82)
Affiliations: Alaska Governor's Interim Commission on Children and Youth -- Commissioner; Alaska Task Force on Medically Fragile/Technology Dependent Children; Alaska ICC's Task Force on Education and Training; ACCH Affiliate -- Cultural/Ethnic Issues Committee
Care Facility: Alaska Native Medical Center -- Anchorage, AK
Experience: Public speaking; conducting training sessions for health care providers/teachers; promoting legislation; First Start -- Coordinator of training for foster parents, child care providers, and respite care providers for infants and toddlers with a chronic illness or disability; working with the State Department of Health and Social Services; cross- and multi-cultural training
Related Employment: Nurse anthropologist by profession; Director, Lifeline Alternatives, Inc. (a non-profit organization which develops and advocates for alternatives to hospitalization or institutionalization for young children with disabilities); Coordinator, Alaska's First Start Training Program; Host, Northwood Bed & Breakfast (fully accessible)
Languages other than English: German, Yupik

Jacqueline Bressers and David Stewart
1427 M Street
Anchorage, AK 99501
907 279-7541
907 274-8287

Child's Disabilities: Visual impairment; cerebral palsy (03/11/86 to 03/26/88)
Affiliations: Interagency Coordinating Council
Care Facility: Children's Hospital -- Seattle, WA
Skills and Interests: Programming that actively supports home care of children with disabilities by providing a full range of support services to the family
Experience: Public speaking; promoting legislation
Related Employment: Attorney, Public Defender Agency

Brenda Trumble
P.O. Box 136
Klawock, AK 99925
907 755-2278

Child's Disabilities: Cerebral palsy (04/03/81)
Affiliations: Interagency Coordinating Council; Ketchikan Association for Parents of People with Special Needs (respite service) -- Board Member; Governor's Council for the Handicapped & Gifted -- Legislative Committee Chairperson; Special Education Service Agency -- Board Member
Care facility: Ketchikan Medical Clinic -- Ketchikan, AK
Skills and Interests: Family support; advocacy
Experience: Establishing a state funded parent coalition; public speaking; training parents; promoting legislation
Related Employment: Adult education -- literacy

ARIZONA

Joanne C. Brownlie
5973 Oak Ridge, H.P.
Prescott, AZ 86301
602 776-8337

Children's Disabilities: One child with Down syndrome; Another with bilateral cleft lip and palate; learning disabilities
Affiliations: Maricopa Advisory Council on Developmental Disabilities -- Board Member; National Down Syndrome Congress; SHARING (Down syndrome parent support group); ARC -- Arizona
Skills and Interests: Information and assistance for families of children and youth with special needs from birth through 21 years; linking parents with other parents and community services; liaison between families and the school district or community agencies
Experience: South Nevada Down Syndrome Organization -- past President; Special Education Parent Advisory Committee -- Representative; public speaking; leading training for health care providers/teachers; promoting legislation; starting or maintaining parent/family support groups; working with state health departments; Arizona Department of Education -- Volunteer Advocate

Linda Diffine'
2413 West Shady Glen Avenue
Phoenix, AZ 85023
602 242-2289
602 866-7501

Child's Disabilities: Nemaline myopathy; chronic respiratory failure
Affiliations: Arizona Chapter of S.K.I.P. -- President and Director; *Pilot Parent Partnerships; Phoenix Children's Hospital -- Parent Advisory Council
Care Facility: Phoenix Children's Hospital -- Phoenix, AZ
Skills and Interests: Home care for children who are technology dependent; parent support groups
Experience: Public speaking; conducting training sessions for health care providers/teachers; promoting legislation; starting or maintaining parent/family support groups

Barbara Hopkins
1005 East Carver Road
Tempe, AZ 85284
602 838-9006

Child's Disabilities: Prune Belly syndrome; scoliosis
Affiliations: Prune Belly Syndrome Parent Network -- Director; Arizona Consortium for Children with Chronic Illness -- Director and Chairwoman; Arizona Joint Legislative Committee on Health Care
Skills and Interests: Parent-to-parent support and advocacy; parent/professional collaboration
Experience: Arizona Consortium for Children with Chronic Illness -- Parent Representative; Children's Rehabilitative Services, Phoenix Children's Hospital -- Parent Advisory Council Member; public speaking; leading training for health care providers/teachers; promoting legislation; starting or maintaining parent/family support groups; working with state health departments
Related Employment: R.N.

Susan Larkin
720 East Brentrup
Tempe, AZ 85283
602 239-4450
602 897-9745

Child's Disabilities: Congenital heart defect (03/21/82)

Affiliations: Arizona Consortium for Children with Chronic Illness; *Pilot Parent Partnerships; S.K.I.P.
Care Facility: Phoenix Children's Hospital -- Phoenix, AZ
Skills and Interests: Financing and education issues; psychosocial needs of children with chronic illness and their families
Experience: Phoenix Children's Hospital -- Parent Advisory Council Member; public speaking; leading training for health care providers/teachers; promoting legislation; working with state health departments to monitor care providers in Arizona; Arizona Consortium for Children with Chronic Illness -- Executive Director
Related Employment: Family Support Coordinator, Patient Relations Department, Phoenix Children's Hospital

Nancy Morgan
*Pilot Parent Partnerships
2150 East Highland, Suite 105
Phoenix, AZ 85016
602 468-3001

Child's Disabilities: Down syndrome (04/04/79)
Affiliations: *Pilot Parent Partnerships -- Program Coordinator, Statewide (Rural) Network; SHARING (Down syndrome parent support group) -- President and Co-founder; ARC -- Education Committee, Public Relations Committee, and Governmental Affairs Committee -- former Member
Care Facility: Private physician
Skills and Interests: Health care insurance for pre-existing conditions; integration; family support
Experience: Serving on Division of Developmental Disabilities Advisory Committees; providing family support staff training and development for Division of Developmental Disabilities; maintaining parent/family support groups; public presentations; providing training to parents, health care providers, and/or educators; promoting legislation

Ruth Tracy
P.O. Box 697
Ganado, AZ 86505
602 755-3411
602 755-6107

Child's Disabilities: Down syndrome (09/15/80)
Affiliations: *Pilot Parent Partnerships; EPICS (Educating Parents with Indian Children)
Care Facility: Sage Memorial Hospital -- Gavado, AZ
Skills and Interests: Parent training
Experience: Parent workshops; parent coordinator; Utah State University -- Task Force for Age 0 to 3 Proposal for Navajo Tribe; maintaining parent network; training parents; promoting legislation
Related Employment: Parent Advocate
Languages other than English: Navajo

Betsy Trombino
*Pilot Parent Partnerships
2150 East Highland, Suite 105
Phoenix, AZ 85016
602 468-3001
602 942-8626

Child's Disabilities: Dwarfism; orthopedic complications; limited mobility
Affiliations: *Pilot Parent Partnerships -- Program Director
Skills and Interests: Parent-to-parent support; parent networking at local, state, and national levels; training of professionals; adolescent-to-adult transition
Experience: Various advisory councils and committees, mostly in the areas of developmental disabilities and health care; working with state health department; American Occupational Therapy Association -- Parent faculty; CAPP Project -- National Resource Parent
Related Employment: Program Director, *Pilot Parent Partnerships

ARKANSAS

Janis Smith
512 East 3rd Street
DeWitt, AR 72042
501 946-1819

Child's Disabilities: Leukodystrophy; scoliosis; mental retardation; quadriplegia; seizure disorder; gastroesophageal reflux; G-tube; severe respiratory problems (02/28/71 to 02/06/90)
Affiliations: National Tay Sachs and Allied Diseases Association -- Co-chair, Parent Peer Group, Board Member, and Executive Committee

Member; United Leukodystrophy Foundation; Arkansas Disability Coalition; Camp Aldersgate -- Little Rock, AR; Jenkins Memorial Children's Center -- Pine Bluff, AR; Children's Medical Services; Arkansas Department of Health; Developmental Disabilities Services; Easter Seals Rehabilitation -- Little Rock, AR
Care Facility: Arkansas Children's Hospital -- Little Rock, AR
Skills and Interests: In-home respite care; finding support groups for families; hospice programs; public awareness
Experience: Parent-to-parent support
Related Employment: Patient-Care Coordinator, Neurology & Rehabilitative Medicine, Arkansas Children's Hospital

CALIFORNIA

Donna G. Albrecht
4603 Lincoln Drive
Concord, CA 94521
415 825-6861

Child's Disabilities: Werdnig-Hoffmann disease (11/05/75)
Affiliations: Werdnig-Hoffmann Parent Support Group; Muscular Dystrophy Association; Families of Spinal Muscular Atrophy
Care Facility: Kaiser -- San Francisco, CA
Skills and Interests: Parent-to-parent support; sports programs for children with disabilities
Experience: Public speaking; leading training for health care providers/teachers; starting or maintaining support groups

Jane Armfield
544 87th Street
Colma, CA 94015
415 992-7095

Child's Disabilities: Congenital central hypoventilation syndrome (CCHS) (12/19/85)
Care Facility: Children's Hospital -- San Francisco, CA
Skills and Interests: State funding for home care for children who are medically fragile
Experience: Leading training for health care providers/teachers; public speaking

Lesly Bird
100 West Cerritos Avenue
Anaheim, CA 92805
714 533-TASK

Children's Disabilities: Pulmonary hypertension; pseudoobstruction of the intestinal track; oxygen dependence (12/07/83); Learning disabilty (04/10/79)
Affiliations: *TASK (Team of Advocates for Special Kids) -- Parent trainer and Information specialist; C.R.I.B.S. (Coordination of Resources to Infants for Better Service) -- the Interagency Coordinating Council for the County of Orange's Early Intervention Program; March of Dimes -- Public Affairs Committee
Care Facility: Children's Hospital of Orange County -- Orange, CA; UCLA -- Los Angeles, CA
Skills and Interests: Training parents/professionals in P.L. 94-142; advocacy for families with children in special education; families in the foster care system; support for families who have children with chronic conditions that require repeated hospitalization
Experience: Interagency Coordinating Council; *TASK -- Parent trainer; serving on Task Force to implement the safe placement of High Risk Foster Infants; starting or maintaining parent/family support groups; public speaking; training parents, health care providers, and teachers; promoting legislation
Related Experience: Parent trainer and Information specialist, *TASK

Lynsee and Robert Cain
4881 Miramar Avenue
San Jose, CA 95129
408 243-2196

Child's Disabilities: Developmental delay; communication handicap (04/04/82)
Affiliations: *Parents Helping Parents -- Founder and Co-facilitator of I.C.N.P.; Parents Who Care, Good Samaritan
Care Facility: Private physicians
Skills and Interests: Respite care
Experience: Starting or maintaining parent/family support groups; public speaking; training parents, health care providers, or teachers
Related Employment: Instructional Aide Substitute
Languages other than English: French

June Carrin
2378 Sutter Street
San Francisco, CA 94115
415 346-6998
415 594-9570
415 728-8013

Children's Disabilities: Two children with Nager's syndrome; Another with severe deafness
Skills and Interests: Support for families; adoption of children with special needs; public awareness of children with special needs
Experience: Public speaking; leading training for health care providers/teachers; promoting legislation; starting or maintaining parent/family support groups; working with state health departments
Related Employment: Clinical psychologist; Owner and operator, Family Options (an independent adoption service)

Joan Cassel
2741 Valley Street
San Francisco, CA 94123
415 346-6858
415 567-4014

Child's Disabilities: Down syndrome
Affiliations: Support for Parents With Special Children -- Executive Director
Care Facility: Children's Hospital -- San Francisco, CA
Skills and Interests: Parent-to-parent support and discussion groups; information and resources for parents; networking with parents of children with similar needs
Experience: Public speaking; leading training for health care providers/teachers; starting or maintaining parent/family support groups; working with state health departments; Parent Outreach Program; resource coordinator
Related Employment: Social worker

Pam Chadwick
6616 Mt. Hope Drive
San Jose, CA 95120
403 295-5175

Children's Disabilities: Attention deficit disorder (10/29/79); Alpha-1-antitrypsin deficiency (02/05/85); Simian creased hand; speech, motor, and cognitive delays; anal stenosis; anoplasty (09/16/86); Hypospadius; thinning of the spinal column
Affiliations: Children's Liver Foundation (Bay Area Chapter) -- President; National CLF -- Director of Family Services; American Liver Foundation; American Lung Association; NORD; MUMS; United Liver Association; Canadian Liver Foundation
Care Facility: University of California -- San Francisco, CA
Skills and Interests: Respite services; recreation programs for brothers and sisters; parent-to-parent support; insurance assistance
Experience: Educating professionals; promoting legislation; working with the social work department at medical centers to form a parent support network for families of children with liver disease; developing a resource packet for families; guest speaking; fundraising

Paul and Marilyn Fox
6312 Zulmida Avenue
Newark, CA 94560
415 794-1859

Children's Disabilities: AIDS (07/20/88 to 07/24/89); AIDS (09/16/87); Prenatal cocaine exposure (09/23/86); Prematurity; acute respiratory distress syndrome; bronchopulmonary dysplasia; gastrostomy tube; aerosol machine; apnea monitor
Affiliations: Center for Attitudinal Healing; Children's Hospital -- Support Group for Children with HIV infection
Care Facility: Children's Hospital -- Oakland, CA
Skills and Interests: Trained for EFH Group for people caring for children with HIV infection
Experience: Emergency foster parent for Alameda County; Children's Home Society; public speaking; training parents and health care providers; promoting legislation

Mari Gooch-Bauhofer
1411 Glendale Avenue
Berkeley, CA 94708
415 549-0317
415 832-7430

Children's Disabilities: Down syndrome; hearing impairment; profound speech delay; ventricular septal defect (VSD) (11/26/82); Attention deficit disorder with hyperactivity

Affiliations: Down Syndrome League; Project COPE (peer parent support); Developmental Disabilities Council of Alameda County
Care Facility: Kaiser Permanente Medical Center -- Oakland, CA
Skills and Interests: Respite care
Experience: Developing workshops on the IEP, developmental steps, behavioral management, and transition; serving on planning committees for respite services and prevention; starting and maintaining family support groups; public speaking; training parents, health care providers, or teachers; promoting legislation; parent and consumer advocate; COPE Coordinator

JoAnn B. Harris
1546 West Escalon
Fresno, CA 93711

Child's Disabilities: Prematurity (06/27/83)
Affiliations: Premie Parent Network -- Chairwoman
Experience: Starting or maintaining parent/family support group

Wayne and Amy Jasper
1272 Mandarin Drive
Sunnyvale, CA 94087
415 852-1678
408 773-1274

Child's Disabilities: Tuberous sclerosis (12/16/82)
Affiliations: National Tuberous Sclerosis Association -- Board Member
Care Facility: University of California -- San Francisco, CA; Kaiser -- Santa Clara, CA
Skills and interests: Respite care; child care; behavior modification
Experience: Developing clinic for tuberous sclerosis and other neurocutaneour disorders at UCSF; Child care task force; starting or maintaining parent/family support groups; training health care providers and teachers

Monica Loose Jones
433 East Pedregosa Street
Santa Barbara, CA 93103

Child's Disabilities: Werdnig-Hoffmann disease
Affiliations: Families of Spinal Muscular Atrophy; SKIP; Leukodystrophy Group
Skills and Interests: All aspects of pediatric home care; comfort care for persons with terminal illness
Experience: State and national task forces on home care of medically fragile children; public speaking; leading training for health care providers/teachers; promoting legislation; working with state health departments
Related Employment: Author, *Home Care for the Chronically Ill or Disabled Child: A Manual & Sourcebook for Parents and Professionals* (New York, 1985, $12.95, available directly from author); Consultant on issues related to pediatric home care
Languages other than English: German; French

Anna Belle Kaufman
1782 Kelton Avenue
Los Angeles, CA 90024
213 445-0939

Child's Disabilities: AIDS; Bronchopulmonary dysplasia; tracheostomy; gastrostomy (deceased)
Affiliations: Good Beginnings; Pediatric AIDS Foundation
Care Facility: Cedars-Sinai Medical Center -- Los Angeles, CA
Skills and Interests: Parent support and networking; reducing trauma of repeated hospitalizations for families
Experience: Author of article for parents on coping with a hospital system; leading training for health care providers/teachers; speaker -- needs of families of children with AIDS; sensitizing parent groups to children with AIDS in schools

Lora A. Keller
1746 Minden Drive
San Diego, CA 92111
619 268-8252
619 571-8488

Child's Disabilities: Cerebral palsy; spastic quadriplegia; prematurity (06/30/81)
Affiliations: Parent to Parent of San Diego County; The Commission for Young Children with Special Needs & Families (for professionals & parents) -- Secretary
Care Facility: Children's Hospital & Health Care Center -- San Diego, CA

Skills and Interests: Respite care services; mainstreaming of infant-preschool aged children; family-centered service delivery; parent/professional collaboration; parent support
Experience: California First Chance Consortium Member; nominated to Interagency Coordinating Council; LPA Parent Team Leader, Trainer, and Consultant
Related Employment: Executive Director, Exceptional Family Resource Center

Linda and Pierre Landry
888 Oneonta Drive
Los Angeles, CA 90065-4125

Child's Disabilities: Monosomy 3P26; muscle fiber disproportion; seizures; moderate to severe hearing loss; vision impairment (03/21/86)
Affiliations: The Association for Persons with Severe Disabilities; Los Angeles Integration Consortium; Los Angeles Unified School District Special Education Commission -- Commissioner; Lanterman Regional Center -- Parent/Professional Group Association; Early Intervention Coordinating Council for Louisiana County -- Parent Representative; Parent Coalition -- Parent Representative
Care Facility: UCLA -- Los Angeles; House Ear Institute
Skills and Interests: Respite care; early intervention; integration
Experience: ICC for Los Angeles; SR9 Task Force; Least Restrictive Environment hearings; parent-professional networking; involved in parent panel that presents to medical students; starting or maintaining parent/family support groups; public speaking; training parents, health care providers, or teachers; promoting legislation
Related Employment: Parent Coordinator, Parent to Parent, University Affiliated Programs -- Los Angeles, CA

Robin LeFrak
888 54th Street
Sacramento, CA 95819

Child's Disabilities: Cleft lip and palate (01/09/85)
Affiliations: Face the Future (support group for children with craniofacial anomalies)
Care Facility: UCD Medical Center
Skills and Interests: Concerns of caring for a child with cleft lip and palate
Experience: Promoting legislation; starting or maintaining parent/family support groups; serving as contact person for parent support group regarding children with cleft lip and/or palate in Sacramento area
Related Employment: Pediatric R.N., UCD Medical Center

Miftah H. MacNeil
562 East 19th Street
Chico, CA 95928
916 891-5865
916 342-7107

Child's Disabilities: Batten disease (juvenile neuronal ceroid-lipofucinosis); visual impairment; cognitive and motor degeneration
Affiliations: ARC (Butte County) -- Family Programs Coordinator; FOCUS (Families of Children Under Stress) -- Co-facilitator; Batten's Disease Research and Support Association
Care Facility: University of California Medical Center -- San Francisco, CA
Skills and Interests: Parent/family support; self-esteem building for families; collaborative programs for parents and professionals; public education for ability awareness; holistic perspectives in care, support, and education
Experience: Community Advisory Committee -- Chairwoman, Butte County Special Education Local Plan Area (SELPA); North California Respite Services Association -- Chairwoman; FOCUS -- Co-facilitator; Special Education, Department of Education, California State University -- Advisory Board on Special Education; Butte County Council on Child Abuse -- Secretary; public speaking; promoting legislation and self-advocacy; starting or maintaining parent/family support groups
Related Employment: Coordinator, Family Support Programs, ARC -- Butte County, CA
Languages other than English: American sign language

Sally Meersman
2841 Highridge Road
La Crescenta, CA 91214
818 249-4261

Child's Disabilities: Williams syndrome (09/09/80)

Affiliations: Williams Syndrome Association -- Membership Director; Lanterman Regional Center -- Parent/Professional Group Association
Care Facility: University of California and Children's Hospital -- Los Angeles, CA
Experience: Frank D. Lanterman Regional Center -- Client Services Committee; LA Countywide Early Intervention Project; P.R.I.C.E. Parenting Program; Foothill SELPA -- Vice President for Parent Training, Community Advisory Committee; starting or maintaining parent/family support groups; public speaking; training parents

Lucia Milburn
3090 Holyrood Drive
Oakland, CA 94611
415 482-5730

Child's Disabilities: Rubinstein-Taybi syndrome (06/22/83)
Affiliations: Project Cope (volunteer peer support to parents)
Care Facility: Children's Hospital Medical Center -- Oakland, CA
Skills and Interests: Peer support; psychological support services; mainstreaming/integration of special children
Experience: Public speaking; conducting training sessions for health care providers, teachers, and peer counselors; promoting legislation; starting or maintaining parent/family support groups; advocacy
Related Employment: Mental Health Worker/Therapist (psychological support to families of children with disabilities), Through the Looking Glass -- Berkeley, CA and Parent-Infant Program, Children's Hospital Medical Center -- Oakland, CA

John and Nancy Moreno-Derks
778 Fig Avenue
Holtville, CA 92250
619 356-4322

Child's Disabilities: Cornelia de Lange syndrome
Affiliations: Cornelia de Lange Foundation; COPE (Community Outreach for Parent Education)
Care Facility: University of California Medical Center -- San Diego, CA; Children's Hospital -- San Diego, CA
Skills and Interests: Expanding educational modes of teaching persons with severe/profound mental retardation
Experience: Public speaking; conducting training sessions for health care providers/teachers; promoting legislation; starting or maintaining parent/family support groups
Related Employment: Counselor for persons with developmental disabilities and mental illness

Ellen Parker
2437 D Street
La Verne, CA 91750
714 593-2827

Child's Disabilities: Down syndrome
Affiliations: ARC Project COPE
Skills and Interests: Parent-to-parent support
Experience: ARC -- Board Member; starting or maintaining parent/family support groups; working with state health departments

Mary Spalding Picchi
6095 Romany Road
Oakland, CA 94618
415 547-1729
415 547-1729

Child's Disabilities: Profound mental retardation
Affiliations: Through the Looking Glass -- Peer Social Work Clinician; Alameda County Developmental Disabilities Council
Care Facility: Children's Hospital of East Bay
Skills and Interests: Helping families of developmentally delayed and at-risk children cope with grief and the psychological, medical, and educational needs of their children
Experience: Public speaking; conducting training sessions for health care providers/teachers; promoting legislation; starting or maintaining parent/family support groups; counseling individual parents, couples, and siblings
Related Employment: M.S.W.; Licensed Clinical Social Worker

Lynn Powell
2700 Azusa, #155
West Covina, CA 91792
818 965-6473

Child's Disabilities: Kidney disease
Affiliations: KIDS (Keys to Introducing

Disabilities in Schools)
Care Facility: UCLA Hospital --
Los Angeles, CA
Skills and Interests: Conducting programs for children and teachers on disabilities; developing family support groups
Experience: Public speaking; leading training for health care providers/teachers; starting or maintaining parent/family support groups; working with state health departments

Florene Stewart Poyadue
535 Race Street, Suite 220
San Jose, CA 95126
408 288-5010
408 251-1987

Child's Disabilities: Down syndrome
Affiliations: *Parents Helping Parents, Inc. -- Executive Director
Skills and Interests: Parent-to-parent support and education; parent/professional collaboration; statewide networks of parent groups across disabilities; training of health and education professionals; sibling programs; Family Friends (senior citizens providing respite for children with special needs)
Experience: Public speaking; leading training for health care providers/teachers; promoting legislation; starting or maintaining parent/family support groups; working with state health departments
Related Employment: R.N.; Marriage Family Child Counselor; Executive Director, *Parents Helping Parents

Karen Rath
350 South San Fernando Boulevard, #105
Burbank, CA 91502
818 841-5475

Child's Disabilities: Trisomy 4P; asthma; seizures; closed brain injury affecting motor abilities; tracheostomy; gastrostomy
Affiliations: Baseline; P.O.N.D. (Parents of Near Drowners)
Skills and Interests: Networking with families of near-drowners; understanding the system
Related Employment: Certified occupational therapy assistant

Georgette Strohm
2694 Kimball Drive
San Jose, CA 95121
408 288-5010

Children's Disabilities: Multiple handicaps (04/07/75); Learning disabilities (07/06/68); Learning disabilities (05/31/71)
Affiliations: *Parents Helping Parents -- Assistant Director, Special Children's Family Resource Center; Interchange: California Parent Educators; Neurofibromatosis Foundation; Hydrocephaly Group; Northern California Coalition -- Advisor (in designing IEP training)
Care Facility: Private physician -- Los Gatos, CA; Stanford Hospital -- Stanford, CA
Skills and Interests: Early intervention; respite care; affordable medical care; integration; education of children with special needs
Experience: Starting or maintaining parent/family support groups; public speaking; training parents, health care providers, or teachers; promoting legislation
Related Employment: Assistant Director, Special Children's Family Resource Center, *Parents Helping Parents
Languages other than English: French

Dorothy Williams
834 22nd Street
Santa Monica, CA 90403
213 855-4431
213 453-2274

Child's Disabilities: Prematurity
Affiliations: Good Beginnings; Parent Care
Care Facility: Cedars-Sinai Medical Center -- Los Angeles, CA
Experience: Coordinating parent support services in the NICU; liaison with parents, social workers, and medical staff; public speaking; leading training for health care providers/teachers; starting or maintaining parent/family support groups
Related Employment: Parent Counselor, Cedars-Sinai Medical Center

Linda E. Williams
3625 Gundry Avenue
Long Beach, CA 90807
213 608-9882
213 426-2418

Child's Disabilities: Congenital heart abnormality (truncus arteriosus)

Affiliations: Parents With Hearts -- Founder and Coordinator
Care Facility: Memorial Miller Children's Hospital -- Long Beach, CA; University of Alabama -- Birmingham, AL (surgeries)
Skills and Interests: Parent/professional collaboration; program development in the hospital; training for health care providers; preparation and education of families for hospital experiences
Experience: Developed hospital program that includes a parent on staff; training for health care providers; establishing a Parent Advisory Board and Family Resource Library; starting and maintaining parent education and support groups; providing parent-to-parent support
Related Employment: Family-Centered Care Coordinator, Memorial Miller Children's Hospital -- Long Beach, CA

Linda Wurzbach
111 Cantas Place
San Ramon, CA 94583
415 829-1853

Child's Disabilities: Spina bifida; hydrocephalus; learning disability
Affiliations: Spina Bifida Association of San Francisco Bay Area; COPE -- Outreach to parents
Care Facility: Kaiser Hospital -- Walnut Creek, CA
Skills and Interests: Special education issues for parents and professionals; collaboration among medical/educational professionals and parents
Experience: State consultant for special education and medical issues; public speaking; training for health care providers/teachers; starting or maintaining parent/family support groups; special education teacher; consulting for parents whose children have died
Related Employment: Parent specialist, State Department of Special Education, 1980-1987

COLORADO

Connie L. Daviet
3032 South Delaware Street
Englewood, CO 80110
303 789-2522

Child's Disabilities: Congenital heart disease
Affiliations: Rocky Mountain Heart Fund for Children -- Program Director; PATCH (Parents Acting Together for Children's Hearts) -- Director
Care Facility: University of Colorado Health Sciences Center -- Denver, CO
Experience: University of Colorado Health Sciences Center -- Ethics Committee Member; Department of Cardiology -- Resource person; public speaking; conducting training sessions for health care providers/teachers; promoting legislation; starting or maintaining parent/family support groups; working with state health departments; advocacy training for families; direct patient assistance

CONNECTICUT

Molly P. Cole
Pediatric Research and Training Center
Department of Pediatrics
University of Connecticut
The Exchange
Farmington, CT 06030
203 674-1485
203 525-3640

Child's Disabilities: Multiple congenital defects
Affiliations: Project CONNECT -- Co-director; Administrative Board of Family Friends; Task Force on Health Impaired Children, Connecticut State Department of Education
Care Facility: Hartford Hospital -- Hartford, CT; University of Connecticut Health Center -- Farmington, CT
Skills and Interests: Improving access to services and service delivery for children with medically complex needs; parent-to-parent support; coordination of community services and system level planning
Experience: Early Intervention teacher for Connecticut Department of Mental Retardation; working with state health department and other health agencies as Coordinator of the Hartford Health/Education Collaborative; public speaking; conducting training sessions for parents and professionals; promoting legislation; developing support and training networks
Related Employment: Project CONNECT -- Co-director, funded by the Maternal and Child Health Bureau

Janet Hine
***CT Parent Advocacy Center**
5 Church Lane
P.O. Box 579
East Lyme, CT 06333
203 739-3089

Children's Disabilities: Cerebellar dysgenesis; ataxic cerebral palsy (12/23/58 and 06/22/60)
Affiliations: *Connecticut Parent Advocacy Center (CPAC), Inc. -- Program Specialist, Newsletter Editor, and Parent Consultant
Skills and Interests: Leading training for parents on their rights and responsibilities under P.L. 94-142; promoting collaboration among parents, educators, and health professionals; providing parents training on issues related to transition from school to work and independent living for young adults with a disability; developing community network systems; providing parent support
Experience: New England SERVE Project -- Connecticut Task Force; Connecticut Department of Health Services -- Bureau of Community Health Advisory Committee; Connecticut Department of Education, Division of Rehabilitation Services -- Statewide Advisory Council and Supported Employment Advisory Committee; Connecticut Transition Steering Committee -- Community Resources Subcommittee Chairwoman; Connecticut TBI Association -- Ad Hoc Committee on Education; starting or maintaining parent/family support groups; public speaking; training parents, health care providers, and teachers; promoting legislation
Related Employment: Parent Consultant, Program Specialist, and Newsletter Editor, CPAC -- East Lyme, CT

Ruth Norton
33 Old Bethel Road
Newtown, CT 06470
203 426-5453

Child's Disabilities: Agenesis of the corpus callosum
Affiliations: Parent to Parent Network of Connecticut -- Founder and former Coordinator; Learning Together; Newtown Citizens with Alternate Needs; New England SERVE
Care Facility: Yale New Haven Hospital -- New Haven, CT; Newington Children's Hospital -- Hartford, CT
Skills and Interests: Parent-to-parent support and education; recreation activities and programs for children with special needs
Experience: Newington Children's Hospital Pediatric Rehabilitation and Training Center -- Advisory Board Member; Newtown Special Education -- Parent/Professional Advisory Board Member; Coordinator, summer program for children with special needs age three to nine; PROBE program aide; public speaking; starting or maintaining support groups

Patricia Tomka
28 Pell Mell Drive
Bethel, CT 06801
203 792-3540
203 798-0403

Child's Disabilities: Mental retardation (11/15/72)
Affiliations: WeCAHR; ARC of Connecticut; Parent to Parent/Greater Danbury area -- Parent Coordinator
Care Facility: Yale-New Haven Hospital -- New Haven, CT; Associated Internists -- Danbury, CT
Skills and Interests: Respite care
Experience: Starting or maintaining parent/family support groups; public speaking; training parents
Related Employment: WeCAHR -- Danbury, CT

Joan Whitten
54 Somerset Drive
Windsor, CT 06096
203 688-0611

Child's Disabilities: Premature birth (25 weeks gestation); ROP (Retinapothy of prematurity); low vision (09/26/86)
Affiliations: Parent Line (support network) -- Program Coordinator
Care Facility: Private physicians -- Hartford, CT
Skills and Interests: Early intervention for children ages zero to three
Experience: Promoting legislation for fifth year funding for P.L. 99-457; starting or maintaining parent/family support groups; public speaking; training parents, health care providers, or teachers
Related Employment: Program Coordinator, Parent Line, Northcentral Birth to Three Service Coordination Center -- Hartford, CT

DELAWARE

Darlene Bonavita
640 Buckson Drive
Dover, DE 19901
302 734-5153

Child's Disabilities: Cerebral palsy; scoliosis; kyphosis; visual impairment (01/24/82)
Affiliations: Parents for the Support of Handicapped Children
Care Facility: Alfred I. Dupont Hospital -- Wilmington, DE
Skills and Interests: Parent-to-parent support
Experience: Public speaking; promoting legislation; starting or maintaining parent/family support groups; working with state health departments

Steven and Anita Klein
509 Pershing Court
Hockessin, DE 19707

Child's Disabilities: Blindness (01/31/88)
Care Facility: Private physician; Duke Eye Center -- Durham, NC; A.I. Dupont Institute -- Wilmington, DE
Skills and Interests: Individualized child and family education service model
Experience: Parent liaison; starting or maintaining parent/family support groups
Related Employment: Anita -- Special Education Teacher, A. I. Dupont Institute

Emily Tarpley
9 Vassar Drive
Newark, DE 19711
302 738-6934

Child's Disabilities: Turner syndrome
Affiliations: Human Growth Foundation, D.C. Chapter -- Board Member and Treasurer
Care Facility: Johns Hopkins University Hospital -- Baltimore, MD
Skills and Interests: Creating a network among genetic groups; prepared an education program for teachers, parents, and professionals about abnormal growth patterns and short stature; psychosocial aspects of short stature
Experience: Assisted in development of Iowa Health Care Guidelines for Families; public speaking; leading training for health care providers/teachers; promoting legislation; starting or maintaining parent/family support groups
Related Employment: Teacher

DISTRICT OF COLUMBIA

Rosalind I. Coleman
241 Ingraham Street, N.W.
Washington, DC 20011
202 687-8807
202 726-6088

Child's Disabilities: Spina bifida (06/30/77)
Affiliations: Spina Bifida Association of America; Children's Hospital National Medical Center -- "Career Day" Committee for Youth with Disabilities
Care Facility: Georgetown University Hospital and Children's Hospital National Medical Center -- Washington, DC
Skills and Interests: Special education advocacy; social needs of children and youth with disabilities; transition of children to teens and adolescents to adulthood
Experience: Developmental Disabiliites Council Committee for Early Intervention; State Advisory Panel for Special Education; starting or maintaining parent/family support groups; public speaking; training parents, health care providers, and teachers
Related Employment: Parent Coordinator for Family Advocacy, Georgetown University Child Development Center

Minna Newman Nathanson
3606 Norton Place, N.W.
Washington, DC 20016
202 775-8826
202 244-5803

Child's Disabilities: Leukemia (deceased)
Affiliations: Candlelighters Childhood Cancer Foundation -- former Director of Programs and Publications
Skills and Interests: Medical and psychosocial information for parents and professionals; early childhood development and education
Experience: Public speaking; training for health providers, teachers, and parent group leaders;

promoting legislation; starting or maintaining support groups; developing publications; author -- *Organizing and Maintaining Support Groups for Parents of Children with Chronic Illness and Handicapping Conditions* (available from ACCH)
Related Employment: Candlelighters Childhood Cancer Foundation; Editor, Mental Health Policy Resource Center

FLORIDA

Ardith F. Brown
3570 Blueridge Drive
Pensacola, FL 32504
904 469-0714

Child's Disabilities: Developmental delay; speech and language impairment (09/81)
Affiliations: Special Parents -- past President and Board Member; *Parent Education Network/Florida (PEN) -- Trainer; Escambia PreKindergarten Interagency Council; Parent Resource Organization -- Chair
Care Facility: Children's Hospital at Sacred Heart -- Pensacola, FL
Skills and Interests: Early intervention
Experience: Florida Interagency Coordinating Council for Infants and Toddlers to assist state in implementing P.L. 99-457 -- Consultant; public speaking; conducting training sessions for health care providers or teachers; promoting legislation; starting or maintaining parent/family support groups

Janet Evans
CMS
Building 6, Room 280
1317 Winewood Boulevard
Tallahassee, FL 32399
904 488-5040
904 385-6244

Child's Disabilities: Developmental disorder; cerebral palsy (02/23/82)
Affiliations: Birth to 3 Network; PRO of Florida
Care Facility: Private practitioner
Skills and Interests: Integration into day care
Experience: Consortium of newborn intervention programs; public speaking; training parents, health care providers, and teachers; promoting legislation
Related Employment: Service Coordinator, CMS

Annette Fogleman
352 East Lake Road
Palm Springs, FL 33461
305 964-4888

Child's Disabilities: One child who had asthma and hypertension; Second child who was premature and had a tracheostomy
Affiliations: The Friendship Connection -- Co-director
Care Facility: Good Samaritan Hospital and St. Mary's Hospital -- West Palm Beach, FL
Skills and Interests: Developing partnerships with medical professionals; educating community on the needs of families
Experience: Public speaking; serving as Parent Liaison to hospital Neonatal and Pediatric Intensive Care Units; database of information for families of children who have special needs; co-founder of non-profit agency for medically fragile children and their families

Joan Gebo
3115 Coral Hills Drive, #D-1
Coral Springs, FL 33065
305 755-7917

Children's Disabilities: Bronchopulmonary dysplasia; tracheostomy; immune deficiency (T & B cell); internal catheter for IV gammaglobulin transfusions (1982); Near-SIDS; gastroesophageal reflux (1984)
Affiliations: SKIP of Florida -- Director
Skills and Interests: Parent networking and support
Experience: Starting or maintaining parent/family support groups
Related Employment: R.N., critical care

Pat Hackett-Waters
7420 Spring Villa Circle
Orlando, FL 32819
407 352-6911

Child's Disabilities: Werdnig-Hoffmann disease (05/24/73)
Affiliations: Families of Spinal Muscular Atrophy; ACCH Parent Network; Parent to Parent of Florida
Skills and Interests: Education; care

management; transition-vocational issues
Experience: Public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; consulting on projects for ACCH and Maternal and Child Health Bureau
Related Employment: M.Ed.; Teacher

Patty Houghland
3312 Longleaf Drive
Pensacola, FL 32526
904 944-3217

Child's Disabilities: Brain damage; seizure disorder; chronic illness; tracheostomy and supplemental oxygen; permanent gastrostomy (07/15/82)
Affiliations: Special Parent Support Group -- former President; Parent to Parent of Florida -- Board Member; *Parent Education Network/Florida (PEN) -- Trained Parent
Care Facility: Spitz Clinic, The Center for Neurological Rehabilitation -- Morton, PA
Skills and Interests: Working with parents in support groups; establishing classes for children with developmental disabilities in the Catholic school system
Experience: Public speaking; conducting training sessions for health care providers and parents; training teenagers in a special sitters program; starting or maintaining parent/family support groups; working with the federally funded child care Continuum of Care Project to mainstream children with special needs into regular day care programs by providing technical assistance and training
Related Employment: Special education teacher for individuals with mental retardation; Elementary teacher

Paula Lalinde
12310 Southwest 92nd Terrace
Miami, FL 33186
305 274-3669

Child's Disabilities: Spina bifida (06/29/84)
Affiliations: Parent to Parent of Miami -- Parent Leader; Parent to Parent of Florida -- State Coordinator; Spina Bifida Association of Southeast Florida -- Area Representative for Dade County; Direction Services -- Advisory Board; Florida's Interagency Coordinating Council for Infants & Toddlers -- Parent Resource Organization Member
Care Facility: Miami Children's Hospital -- Miami, FL
Skills and Interests: Working with hospitals and community agencies to build support for parents of children with disabilities; planning for P.L. 99-457; developing culturally sensitive programs
Experience: Instrumental in starting Parent to Parent of Miami; seeking funds to translate advocacy training and educational materials into Spanish; public speaking; conducting training sessions for health care providers/teachers; promoting legislation; developing mentor program for children with special needs with Big Brothers/Big Sisters; developing outreach project for Haitian families who have children with special needs
Related Employment: Education
Languages other than English: Spanish

Ronnie Londner
P.O. Box 56-1111
Miami, FL 33156
305 232-0381
305 232-0381
305 232-9890 (fax)

Child's Disabilities: Intraventricular hemorrhage (IVH); cerebral palsy
Affiliations: Parent Care, Inc. -- former NationalBoard Member; Parent to Parent of Miami -- Board of Directors; ARC -- Children and Youth Advisory Board; IVH Parents -- Founder
Care Facility: Miami Children's Hospital -- Miami, FL
Experience: Public speaking; conducting training sessions for health care providers/teachers; promoting legislation; starting or maintaining parent/family support groups; reviewed federal grants for Maternal and Child Health Bureau, Department of Health and Human Services; Medline researching
Languages other than English: German; Spanish

Diana Sue Mathews
4805 Southwest 45th Street
Gainesville, FL 32608
904 378-1827

Child's Disabilities: Choreoathetosis cerebral palsy; epilepsy; autism; mental retardation (10/25/73)
Affiliations: *Parent Education Network/Florida (PEN); Parent to Parent of Florida -- Board Member; Parent to Parent of Alachua County -- Parent Coordinator; Sidney Lanier School (Special Education) -- SAC Chairperson and past PTA President; ARC; Very Special Arts Festival of Alachua County -- Advisory Board; ARC of Alachua County -- Board Member; The School Board of Alachua County's Parent Services Project -- Partners Advisory Board; Board of Alachua County Commissioners -- Citizens Handicap/Disability Advisory Committee
Care Facility: Medical Gardens -- Gainesville, FL
Skills and Interests: Advocating for improved child health care, nutrition, and quality education for children; improving coordination of services; health care financing for families of moderate means; respite care
Experience: Involved in grants for early intervention, transition, and parent services; working with the health department to make referrals for parent-to-parent support; public speaking; conducting training sessions for health care providers/teachers; promoting legislation; starting or maintaining parent/family support groups; developing respite care program; serving on preschool Interagency Council and Life Lab Transition Project Council; volunteer work at Sunland Center; private tutoring of persons with academic learning problems
Related Employment: Writer, *Special Education Leadership* and *Handicapped News*; Consultant on Parent Services Project to develop a directory of services for persons with disabling conditions and their families; Consultant, Department of Education for State of Florida to collect P.L. 99-457 data

Mr. and Mrs. Ronald Medler
1100 Southwest 4th Avenue, #15B
Delray Beach, FL 33444
407 278-9707

Child's Disabilities: Kawasaki disease (mucocutaneous lymph node syndrome) with resulting heart aneurysm (10/11/84)
Care Facility: Miami Children's Hospital -- Miami, FL; Boca Raton Pediatric Associates -- Boca Raton, FL
Skills and Interests: Public education about rare diseases; forming parent support networks around rare diseases

Frank and Nicol Shulman
1271 South Cypress Road
Pompano Beach, FL 33060
305 942-9345
305 942-0394

Child's Disabilities: Down syndrome (01/12/80)
Affiliations: National Down Syndrome Foundation; Houses for the Handicapped; Girl Scouts; Okinawan Karate (special classes for persons with mental retardation)
Care Facility: Pompano Pediatric Clinic and North Broward Hospital -- Pompano Beach, FL
Skills and Interests: Massage therapy
Experience: Starting or maintaining parent/family support groups; public speaking; training health care providers
Related employment: Massage therapy, Massage Therapy Clinic

Jonathan and Kathie Basten
1136 Sandalwood Circle
Niceville, FL 32578

Child's Disabilities: Spina bifida (02/02/89)
Affiliations: Parent-to-Parent
Care Facility: Nemours Children's Foundation -- Jacksonville, FL
Skills and Interests: Financing; early intervention; preventative health care; parent education
Experience: Parent-to-Parent conference; family focus on IEP's PEN; public speaking; training parents

Elizabeth Stanley
Route 5 Box 185
Williams Road
Defuniak Springs, FL 32433
904 892-2803

Child's Disabilities: Down syndrome (09/22/79); Multiple hip surgeries -- dislocation (congenital)
Affiliations: Parent to Parent of Florida; Walton

County Parent to Parent -- Founder and Coordinator; Infant Learning Project -- Volunteer Parent Aide; NDSC; Florida Advocacy Coalition Excellence (F.A.C.E.); Guard, Inc. -- Parent Member, Board of Directors
Care Facility: The Children's Hospital -- Boston, MA
Skills and Interests: Early childhood development; early intervention; parent/professional liaison in hospital and school settings
Experience: Public speaking; conducting training sessions for health care providers/teachers; promoting legislation; starting or maintaining support groups; started Interagency Council including parents, professionals, and school board members; working with the health department's Child Protection Team on their "Prevention Project" and "Infant Learning Project;" due process; Florida State University Special Education Department -- Parent Consultant
Related Employment: Nurse

Leigh Ware
1005 Bartow Avenue
Pensacola, FL 32507
904 474-7656
904 455-1059

Child's Disabilities: Persistent fetal circulation at birth; attention deficit disorder (08/19/78)
Affiliations: Parent Care, Inc. -- Board of Directors, Public Relations Chairperson; Parent to Parent of Florida; Veteran Intensive Care Parents (VIPS) -- Founder; National Association of Neonatal Nurses; March of Dimes -- former Board of Directors; Florida Consortium for Newborns; NAACOG
Care Facility: Sacred Heart Hospital -- Pensacola, FL
Skills and Interests: Long-term follow-up during school years; parent-to-parent support; early intervention
Experience: Training local Parent to Parent peer counselors; coordinating and presenting a parent advocacy legislative workshop; coordinating weekly parent support group in Neonatal Intensive Care Unit; Governor's Constituency for Children; Florida Consortium for Newborn Interventions; starting or maintaining parent/family support groups; public speaking; training parents, health care providers, or teachers; promoting legislation
Related Employment: Parent Support Coordinator for the NICU and part-time staff nurse, Sacred Heart Hospital -- Pensacola, FL

Connie Wells
P.O. Box 2113
Wauchula, FL 33873

Children's Disabilities: Seizure disorder (10/04/74); Autonomic dysfunction/learning disability (01/19/81); Autonomic dysfunction (05/26/82)
Affiliations: Parent to Parent of Florida -- Secretary; Parent to Parent of Hardee County -- Organizer; CMS -- Consultant on state level
Care Facility: Children's Medical Services -- Lakeland, FL
Skills and Interests: Respite care; legislation; P.L. 99-457; special education; family support; adolescent self esteem; financing home care; cultural/migrant needs
Experience: ACCH Editorial Board; Michigan Interagency Coordination Council; Parent Resource Organization; Hardee County ESE Advisory Board; Family Resources Planning Team; 99-457 Prevelance Cost Study Advisory Board; HRS Case Management Team; National Coordinating Council Chairs; starting or maintaining parent/family support groups; public speaking; training parents, health care providers, or teachers; promoting legislation
Related Employment: Family Advocate

Nancy Wilks
422 Northwest Concord Drive
Pt. St. Lucie, FL 34983
407 878-3284

Child's Disabilities: Profound mental retardation (07/10/77)
Affiliations: Parent to Parent of St. Lucie County -- President; *Parent Education Network/Florida (PEN) -- Certified Master Trainer; Parent to Parent of Florida -- past Board Member
Skills and Interests: Worked successfully with the school system to develop a new, early, special education center in our county; providing local child advocacy services
Experience: Public speaking; promoting legislation; starting or maintaining parent/family support groups; serving as a parent representative on a committee to revise Admission and Placement Procedures for Exceptional Student Education; working to have vocational education programs available for students with mental retardation
Related Employment: Teacher of children who have mental retardation; substitute teacher

GEORGIA

Marlene R. Harrington
1619 Flat Shoals Road
Milledgeville, GA 31061
912 452-4428

Child's Disabilities: Neurofibromatosis; pseudoarthrosis of the tibia; amputation of the right foot
Affiliations: Shriner's Hospital
Care Facility: Shriner's Hospital -- Greenville, SC
Skills and Interests: Educating the public about children with special needs; parent-to-parent support for parents of children with special needs
Experience: Speaker on topics of positive self-awareness and self-esteem
Related Employment: Freelance speaker and companion for elderly

Cheryl Knight
1851 Ram Runway Drive
College Park, GA 30337
404 761-3150
404 627-5318

Child's Disabilities: Attention deficit disorder/hyperactivity (11/29/81)
Affiliations: *Parents Educating Parents (PEP)
Skills and Interests: Respite services; resource and information services
Experience: Serving on respite committee task force; working with departments of human resources and public health; starting or maintaining parent/family support groups; public speaking; training parents, health care providers, or teachers
Related Employment: Project Coordinator, CAPP Project and NEC*TAS Project

Vickie D. Polk
3773 Sharon Drive
Powder Springs, GA 30073
404 761-2745

Child's Disabilities: Cerebral palsy (12/05/87)
Care Facility: Military Hospital Clinic
Experience: Public Speaking; training parents, health care providers, or teachers
Related Employment: *Parents Educating Parents (PEP) -- Staff Member; ARC of Georgia

HAWAII

Kathy F. Campbell
1046 Lunaai Street
Kailua, HI 96734
808 261-5049

Child's Disabilities: Cerebral palsy (1966)
Skills and Interests: Parent advocacy; legislative lobbying; system changes; advising other parents; parent training
Experience: Working with state health department; DD Council -- Chairwoman; DD Branch -- Advisory Committee Chairwoman; public speaking; conducting training sessions for health care providers/teachers; promoting legislation; starting or maintaining parent/family support groups
Related Employment: Teacher, Special Education, State Department of Education

Emma K. Cappadonna
582 Hahaione Street, #E
Honolulu, HI 96825-1410
808 536-3764
808 395-4582

Child's Disabilities: Cerebral palsy; seizures
Affiliations: Sultan Easter Seal School -- Mothers' Support Group and Therapy Assistant, Birth to Three Program
Care Facility: Easter Seal Society -- Honolulu, HI
Skills and Interests: Lobbying for parent needs

Colleen D. Conner
77-6346 Halawai Place
Kailua-Kona, HI 96740
808 323-3881
808 329-6383

Children's Disabilities: Hirschsprung's disease (01/15/83); Down syndrome (11/20/86)
Affiliations: Kona Child Development Program -- Care Coordinator; West Hawaii Family Forum
Care Facility: Cedar Sinai -- Los Angeles, CA; Kaiser -- Kona Clinic
Skills and Interests: Grant writing; respite care; early intervention; transition to DOE
Experience: Starting or maintaining parent/family support groups; public speaking

Related Employment: Parent Involvement Specialist/Care Coordinator, Kona Child Development Program
Languages other than English: Spanish

Myra T. Daquioag
6444 A 102 Street
Ewa Beach, HI 96706
808 455-4169
808 499-1391

Child's Disabilities: Global developmental delays (06/17/85)
Care Facility: Tripler Army Medical Center
Related Employment: Care Coordinator, Leeward Infant & Toddler Program
Languages other than English: Filipino (Tagalog)

Carolyn Gire
5628 Halekamani Street
Honolulu, HI 96821
808 944-3563
808 377-9628

Child's Disabilities: Turner syndrome; aortic stenosis
Affiliations: "Kardiac Kids" (Parent Support Group); Human Growth Foundation -- Hawaii Chapter
Care Facility: The Queen's Medical Center -- Honolulu, HI
Experience: Working with local health planning council on "Certificate of Need" Committee
Related Employment: Health insurance marketing; dependent care assistance plans

Jody W. Hill
P.O. Box 551
Kula, HI 96790
808 244-7467
808 878-6166

Child's Disabilities: Prematurity; respiratory distress syndrome; congestive heart failure; failure to thrive (10/13/80)
Affiliations: Molokai Mom's Group (Imua Rehab) -- Facilitator; Project AWARE; Healthy Mothers, Healthy Babies -- Maui Chapter
Care Facility: Maui Medical Group -- Wailuku, HI
Experience: Writing training module on Maternal Infant Bonding in the NICU; Zero to Three Hawaii Project -- Development/implementation of the IFSP; Child Care Task Force; Mayor's Advisory Committee on the Handicapped; foster mother; Maui County Developmental Disabilities Committee; Family Forum -- Human Services Research Institute -- Oregon; starting or maintaining parent/family support groups; public speaking; training parents, health care providers, and teachers; promoting legislation
Related Employment: Parent Involvement Specialist, Zero to Three Hawaii Project, Imua Rehab -- Wailuku, HI

Gordon K. Kakalia
49 Ihea Place
Pukalani, HI 96788
808 572-7225

Child's Disabilities: Blindness; cerebral palsy; seizures
Affiliations: IMPACT (In Many Parents and Children Together) -- Executive Director; *Hawaii Association for Children and Adults with Learning Disabilities (HACALD); Developmental Disabilities Committee -- Agency Representative
Care Facility: Paia Special Education School -- Paia, HI
Skills and Interests: Changing or creating services to suit the needs of children; monitoring agencies; public involvement; parent training
Experience: Public speaking; conducting training sessions for health care providers, teachers, and parents; promoting legislation; starting or maintaining parent/family support groups; working with the state health department

Karen Ululani Kameenui
835-H Olokele Avenue
Honolulu, HI 96816
808 536-3764
808 732-0964

Child's Disabilities: Hunter syndrome (11/25/70 to 03/06/81)
Care Facility: Kapiolani Women's and Children's Medical Center -- Honolulu, HI
Experience: Conducting training sessions for health care providers/teachers; conducting mothers' support groups
Related Employment: Classroom assistant and Parent worker, Infant Stimulation Program

Suzanne Kashiwaeda
P.O. Box 862
Kalaheo, HI 96741
808 245-6983
808 232-8406

Child's Disabilities: Seizure disorder; developmental delays; congenital brain damage (11/17/79)
Affiliations: Birth to Three Network; Parents with Special Kaeikis; Mayor's Advisory Committee for People with Disabilities
Care Facility: Public school system
Skills and Interests: Early intervention; parent training
Experience: Interagency Coordinating Council; parent advisory committees; physician training project; starting or maintaining parent/family support groups; public speaking; training parents, health care providers, and teachers; promoting legislation
Related Employment: Family Involvement Specialist, Kawai Easter Seal Society

Marion T. Leong
3457 Ala Hinalo Street
Honolulu, HI 96818
808 847-2565
808 839-4046

Children's Disabilities: Epilepsy (07/23/61); Severe mental retardation (grandsons -- 10/31/83 & 10/31/85)
Affiliations: Special Parent Information Network (SPIN); Po'ohala
Care Facility: Kapiolani Women's and Children's Hospital and Straub Clinic -- Honolulu, HI
Skills and Interests: Public health education in developmental disabilities
Experience: Department of Education -- Educational assistant and Special Education Teacher; PONA Program, Honolulu Community College -- working with adults with disabilities; starting or maintaining parent/family support groups; public speaking; training parents, heatlh care providers, or teachers
Related Employment: Special Education Teacher/Care Coordinator, Lanakila Infant and Toddler Development Program

Paula Scott Malia
345 C Kalama Street
Kailua, HI 96734
808 263-0235

Child's Disabilities: Rett syndrome (08/20/81)
Care Facility: Tripler Army Medical Center -- Honolulu, HI

Mary Nakasuji-Yoshino
962 Lunahelu Street
Kailua, HI 96734
808 531-3511
808 263-4626

Child's Disabilities: Prematurity
Affiliations: Sultan Easter Seals School -- Parent Group; Monitor Sitters
Care Facility: Kapiolani Women's and Children's Hospital -- Honolulu, HI
Skills and Interests: Support services for parents of premies; stresses of bringing infants home with a monitor; breastfeeding/La Leche program while in hospital and at home; family dynamics after disability
Experience: Public speaking; conducting training sessions for health care providers/teachers; starting or maintaining parent/family support groups
Related Employment: Social Worker, Rehabilitation Hospital of the Pacific
Languages other than English: Japanese

John and Pattie Nishimoto
324B Kalama Street
Kailua, HI 96734
808 957-0066 (Pattie)
808 536-1015 (John)
808 262-2456

Child's Disabilities: Bilateral cleft lip and palate (02/13/87)
Affiliations: Birth to Three Parent Network; National Association of Social Workers; Beginning At Birth, Inc. (BABI) -- Founder; ACCH
Care Facility: Kapiolani Medical Center for Women and Children -- Honolulu, HI; Los Angeles Hospital for Children -- Los Angeles, CA
Skills and Interests: Care coordination in relation to the IFSP; parent/professional partnerships; enhancing professional awareness

and sensitivity toward families of children with special needs; promoting parent involvement in the legislative process; financing health care and education for children with special needs; transportation issues; due process/mediation options for families; issues relating to cultural sensitivity; improving hospital relations when children are hospitalized
Experience: Developmental Disabilities Division, Hawaii Department of Health -- former Social Worker; Easter Seal Society of Hawaii -- former Social Worker/Program Director; Zero-to-Three Hawaii Project, Department of Health -- former Parent Coordinator; local and national public presentations; conducting training for health care providers/teachers; promoting legislation; facilitating family support groups
Related Employment: Social Worker, Zero-to-Three Hawaii Project to provide technical consultation on care coordination and IFSP activities

Susan Rocco
98-697E Kaonohi Street
Aiea, HI 96701
808 548-7606
808 488-5532

Child's Disabilities: Mental retardation; seizure disorder; atypical pervasive developmental disorder; cerebral palsy; transposition of the great vessels; pulmonary stenosis (03/29/81)
Affiliations: Special Parent Information Network -- Coordinator; State Interagency Coordinating Council (PL 99- 457) -- Vice Chairwoman; AWARE Board; Home Care Advisory Board; Lanakila Crafts Board of Trustees
Care Facility: Straub Clinic -- Honolulu, HI
Skills and Interests: Parent training in advocacy, future planning, and rights and responsibilities under P.L. 94-142; community resources
Experience: Public speaking; conducting training sessions for health care providers/teachers (as part of parent training efforts); working with the state health department on Commission on the Handicapped and the Interagency Coordinating Council
Related Employment: Program Specialist, Coordinator of the Special Parent Information Network (SPIN)

Pleaman and Marci Shaver
45-227 Koa Kahiko Street
Kaneohe, HI 96744
808 235-7869

Child's Disabilities: Astrocytoma brain tumor; hypopanpituitaryism (05/10/81)
Affiliations: H.U.G.S. (Help Understanding and Group Support for Hawaii's Seriously Ill Children)
Care Facility: Honolulu Medical Group Windward -- Kailua, HI; Kapiolani Medical Center -- Honolulu, HI
Skills and Interests: Respite care; financial aid
Experience: Ohana Kokua (parent lobbying group) -- Honolulu, HI; public speaking; promoting legislation
Related Employment: Volunteer, Respite Care Task Force

Nana Silva
1618 Houghtailing Street
Honolulu, HI 96817
808 536-1015
808 845-8656

Child's Disabilities: Rubella; deafness; blindness; mentally retardation
Affiliations: Easter Seal Society of Hawaii -- Fund Raiser
Care Facility: Straub Clinic -- Honolulu, HI
Experience: Fundraising
Related Employment: Teacher aide, Sultan Easter Seal School -- Honolulu, HI

Constance K. Smith
419 Keoniana Street, #804
Honolulu, HI 96815
808 547-2707
808 949-1999

Child's Disabilities: Down syndrome (02/07/77)
Affiliations: Hawaii Down Syndrome Parent Group -- President; National Down Syndrome Congress; Association for Retarded Citizens; Special Parent Information Network; Aloha Special Technology Access Center (computer education program)
Care Facility: Health Plan Hawaii (HMSA) -- Honolulu, HI
Experience: Starting or maintaining parent/family support groups

Jeanne Watai
1172 Kilauea Avenue
Hilo, HI 96720
808 961-3081
808 969-2017

Child's Disabilities: Autism (05/27/75)
Affiliations: Families as Allies -- County Coordinator; Family Support Network
Care Facility: Hilo Medical Group -- Hilo, HI
Skills and Interests: Respite care
Experience: Starting or maintaining parent/family support groups; training parents, health care providers, or teachers
Related Employment: Respite Services Coordinator, Easter Seal Society

Josie Woll
378 Mamaki Street
Honolulu, HI 96821
808 536-3764
808 373-9713

Child's Disabilities: Encephalomyelomeningocele; agenesis of the cerebellum; hydroencephaly/shunted; neuromuscular scoliosis/spinal fusion; developmental delays
Affiliations: Sultan Easter Seals School -- School Director, Infant Program; Zero-to-Three Hawaii Project
Care Facility: Kapiolani Women's and Children's Medical Center -- Honolulu, HI
Skills and Interests: Parent support and training, especially in rights/advocacy; legislative issues/funding; networking; case management; prevention and intervention
Experience: Public speaking; conducting training sessions for health care providers/teachers; promoting legislation; starting or maintaining support groups; working with the state health and education departments on the Hawaii Stress Center's "Project Bridge" -- Parent Representative; Parent Selection Committee, Zero-to-Three Hawaii -- Co-chairperson (To ensure parent participation in selection process, several parents formulated and implemented standardized interview questions for parent and professional staff being hired by Hawaii Zero-to-Three)
Related Employment: Registered Nurse; School Director, Infant Program, Sultan Easter Seals School

IDAHO

Blenda Davis
3115 North 30th
Boise, ID 83703
208 377-8049
208 342-0399

Child's Disabilities: Mucopolysachridosis sanfilipo B (06/19/81)
Affiliations: *Idaho Parents Unlimited, Inc. (IPUL)
Care Facility: St. Lukes Medical -- Boise, ID
Skills and Interests: Critical illness or medically fragility; respite care
Experience: Testifying for legislators; public speaking; promoting legislation
Related Employment: Office Manager, *Idaho Parents Unlimited, Inc.

Beth Eloe-Reep
1970 Belmont Avenue
Idaho Falls, ID 83404
208 523-3572

Child's Disabilities: Cleft lip and palate
Affiliations: *Idaho Parents Unlimited, Inc. (IPUL) -- Regional Parent Consultant; Parent to Parent
Care Facility: Primary Children's Hospital -- Salt Lake City, UT
Skills and Interests: Parent support
Experience: Region VII Infant/Toddler Committee -- Planning and implementing P.L. 99-457; Children's Special Health Program, Idaho H&W -- Parent representative; starting or maintaining parent/family support groups; public speaking; training parents, health care providers, or teachers; promoting legislation
Related Employment: Regional Parent Consultant, *Idaho Parents Unlimited, Inc.
Languages other than English: Signed English

Lorena Freund
3309 East Pinehill Drive
Coeur D'Alene, ID 83814
208 667-6409
208 667-8082

Child's Disabilities: I-cell disease (deceased)
Affiliations: PROP (Parents Reaching to Other Parents)

Care Facility: Sacred Heart Hospital -- Spokane, WA
Skills and Interests: Parent-to-parent support
Experience: Public speaking; leading training for health care providers/teachers; starting or maintaining parent/family support groups

Christine Rawlings
195 West 3600 S.
Preston, ID 83263
208 852-3093

Child's Disabilities: Cerebral palsy (03/09/83)
Affiliations: Franklin County Parent Support Group -- Parent Contact; *Idaho Parents Unlimited, Inc. (IPUL) -- Regional Parent Consultant
Care Facility: Children's Special Health -- Pocatello, ID
Experience: Starting or maintaining parent/family support groups; public speaking; training paretns, health care providers, and teachers; promoting legislation
Related Employment: Regional Parent Consultant, *Idaho Parents Unlimited, Inc.

Reggie Smolik Swindle
Box 1594
Hailey, ID 83333
208 788-3084

Child's Disabilities: Down syndrome (01/06/87)
Affiliations: *Idaho Parents Unlimited, Inc. -- Region V Parent Consultant; Region V Infant/Toddler Committee -- Public Awareness Subcommittee Co-chair; Blaine County Parents-for-Parents Support Group -- Co-facilitator; Blaine County Medical Center -- R.N.
Care Facility: Blane County Medical Center and Family Practice Association -- Hailey, ID
Skills and Interests: Educating parents of children with special needs on advocacy; general public awareness
Experience: Starting or maintaining parent/family support groups; public speaking; training parents, health care providers, and teachers; promoting legislation
Related Employment: R.N., Blaine County Medical Center

ILLINOIS

Artur and Faye Manaster Eldar
8331 Kimball Avenue
Skokie, IL 60076
312 939-3513 (Faye)
708 934-6191 (Artur)
708 677-3769

Child's Disabilities: Deaf-blind; cerebral palsy (07/31/81)
Affiliations: Keshet: Jewish Families of Children with Special Needs -- past President; Canadian Deaf-Blind and Rubella Association; International Association for the Education of the Deaf-Blind; Sense (British Deaf-Blind Society); National Coalition on Deaf-Blindness; Association for the Education and Rehabilitation of the Blind and Visually Impaired; Hebrew Association of the Deaf; Children's Memorial Hospital -- Consultant, Child Life Department
Care Facility: Children's Memorial Hospital -- Chicago, IL
Skills and Interests: Parent outreach; reaching and serving underserved populations; information and referral; parent-to-parent support; preparation for hospitalization; early childhood special education/early intervention
Experience: Public speaking; conducting training sessions for health care providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments; consulting in early childhood special education with emphasis on pediatric special education; consultant to hospital child life department; Illinois Early Childhood Staff Development Coordination Committee; Chicago Association for the Education of Young Children with Special Needs Commission; Illinois Hearing Impaired Mental Health Advisory Board
Related Employment: Faye -- Special educator; Family Support Pilot Project Coordinator, *Coordinating Council for Handicapped Children
Languages other than English: Faye -- Hebrew; American sign language; Artur -- Hebrew; Polish; Russian; American sign language; Esperanto

Manuela Estrada
1416 North Fair Field Highway
Chicago, IL 60622
312 278-1817

Child's Disabilities: Spina bifida (02/14/87)
Affiliations: Spina Bifida Outreach Program;

Children's Memorial Hospital -- Volunteer Parent, Outreach Program
Care Facility: Children's Memorial Hospital -- Chicago, IL
Experience: Starting or maintaining parent/family support groups
Languages other than English: Spanish

James Green
1730 Hinman Road, #4A
Evanston, IL 60201
312 864-9533

Child's Disabilities: Chronic depression; osteoarthritis; pernicious anemia
Skills and Interests: Film production; films and media materials about children with disabilities; training in media access and preparation of presentations
Experience: Developed, produced, and directed 14-year media campaign for USDE-OSERS (Closer Look, NICHCY); Easter Seals -- Advisory Board Member; National ARC -- Board Member; TAPP Advisory Board -- Chairman; public speaking; leading training for health care providers/teachers
Related Employment: Consultant, James Green Associates; Public Information Media Services

Margaret Ieronimo
333 Country Lane
Glenview, IL 60025
708 729-0701

Child's Disabilities: Miller syndrome (postaxial acrofacial dysostosis) (05/24/89)
Care Facility: Children's Memorial Hospital -- Chicago, IL
Skills and Interests: Increasing accessibility of information for parents and professionals on Miller syndrome
Experience: Starting or maintaining parent/family support groups

Audrey Lewis
1386 Glencoe Avenue
Highland Park, IL 60035
312 432-0594

Child's Disabilities: Werdnig-Hoffmann disease
Affiliations: Families of Spinal Muscular Atrophy -- President
Care Facility: Shriners Hospital, Weiss Memorial, and Children's Memorial -- Chicago, IL
Skills and Interests: Increasing public awareness; parent-to-parent support
Experience: Working on videotape of exercises for children with physical disabilities and able-bodied children

Carmen Maya
1214 West Granville
Chicago, IL 60660
312 465-4865

Child's Disabilities: Down syndrome (06/17/88)
Affiliations: NADS; ACCH; Lakeview Learning Center; Sinner; Institute for the Study of Developmental Disabilities -- Resource Parent
Care Facility: Infant Welfare Society -- Chicago, IL
Skills and Interests: Early intervention
Experience: *Coordinating Council for Handicapped Children -- Parent advocate training program; maintaining parent/family support groups; public speaking; training parents, health care providers, or teachers; promoting legislation
Related Employment: Parent advocate
Languages other than English: Spanish

INDIANA

Dawn Curlee Carlson
20 McKinley Boulevard
Terre Haute, IN 47803
812 231-8337
812 234-4055

Child's Disabilities: Autism (12/31/84)
Affiliations: Autism Society of America -- Wabash Valley Chapter; Parent-to-Parent groups for families of young children -- Facilitator; Indiana Families Uniting -- Secretary and Executive Committee Member
Care Facility: AP&S Clinic -- Terre Haute, IN
Skills and Interests: Parent/professional partnerships; early intervention and early diagnosis
Experience: Vigo County Early Intervention Council -- Site Coordinator, Parent/Progessional Communication Regional Workshop; Special Education District Preschool Advisory Council;

Integration for Children with Autism -- Inservice Panel; starting or maintaining parent/family support groups; public speaking; training parents, health care providers, and teachers; promoting legislation
Related Employment: Coordinator, First Steps Family Referral -- Terre Haute, IN

Linda Hankins
1511 Maria Lane
Plainfield, IN 46168
317 839-6201

Child's Disabilities: Down syndrome
Affiliations: Indiana Parent Information Network, Inc. (IPIN); Riley Hospital for Children -- NICU Parent Liaison Coordinator; Down Syndrome Support Association of Central Indiana
Care Facility: James Whitcomb Riley Hospital for Children -- Indianapolis, IN
Skills and Interests: Working to mandate special education 0 to 5-year olds; establishing parent training center; public awareness
Experience: Indiana Task Force on Early Childhood Special Education -- Parent Coordinator; public speaking; leading training for health care providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments; Riley Hospital for Children -- Parent Support Coordinator; helped to found the IPIN; working with the state education and mental health departments; Indiana University -- IFSP training workshop leader

Claudia and Dan Ippolito
1417 Lennox Street
Anderson, IN 46012
317 643-8627

Children's Disabilities: Fragile X syndrome (05/23/85 and 06/16/87)
Care Facility: Private physicians
Skills and Interests: Respite care; insurance/Medicaid eligiblity; financial needs of families with special needs; early intervention (P.L. 99-457); special education needs of children wtih Fragile X
Experience: Madison County Interagency Coordinating Council (99-457) -- Vice Chair; forming the Indiana Fragile X Resource Center; public speaking; training parents in childbirth education; promoting legislation

Joyce Jones
5005 Dickson Road
Indianapolis, IN 46226
317 542-0582

Child's Disabilities: Spina bifida
Affiliations: Spina Bifida Association of Central Indiana -- President
Care Facility: James Whitcomb Riley Hospital for Children -- Indianapolis, IN
Skills and Interests: Parent-to-parent support; newsletter editor
Experience: Public speaking; maintaining support groups

Ruth Kimberley
1806 Indiana Avenue
Vincennes, IN 47591
812 882-0375

Child's Disabilities: Hunter syndrome
Affiliations: Knox County Advocates for Special Kids -- Founder; National MPS Society, Inc. -- Midwest Region Chairperson; local ARC -- Board Member; Wish Upon A Star, Inc. -- Board Member; Indiana Parent Information Network -- Board Member; Knox County Special Education Advisory Council Member
Care Facility: James Whitcomb Riley Hospital for Children -- Indianapolis, IN
Skills and Interests: Parent/professional collaboration; educating medical profession
Experience: Public speaking; promoting legislation; starting or maintaining support groups; working with state health departments

Nancy M. L. Munson
1239 Hoover Lane
Indianapolis, IN 46260
317 255-9775

Child's Disabilities: Werdnig-Hoffmann disease
Affiliations: Muscular Dystrophy Support Group
Care Facility: Methodist Hospital -- Indianapolis, IN
Skills and Interests: Parent-to-parent mentor programs
Experience: Various committees for Special Education Division, Department of Education -- Parent Advocate Representative; Crossroads Rehabilitation Center -- Parent-to-Parent Mentor Program and Family Advisory Council Member

Donna Olsen
2107 East 65th Street
Indianapolis, IN 46220
317 257-8683

Child's Disabilities: Two children with cystic fibrosis
Affiliations: Riley Children's Hospital -- Parent Advisory Board; Great Lakes Regional Genetics Group -- Steering Committee; Central Indiana Parent Support Group for Cystic Fibrosis -- Co-founder; The Indiana Parent Information Network, Inc. -- President; Directions Services Project -- President
Care Facility: James Whitcomb Riley Hospital for Children -- Indianapolis, IN
Skills and Interests: Parent/professional collaboration; increasing awareness of needs of children with chronic conditions in hospital, school, and community; medical education; child development
Experience: Public speaking; conference planning; starting or maintaining support groups; working with state health education departments; community organizing around issues for children; state and community planning committees; medical education; legislative advocacy
Related Employment: Community Support Consultant, First Steps, Department of Mental Health

Beverly Preske
2835 West Boonville-New Harmony Road
Evansville, IN 47720
812 963-9010

Child's Disabilities: Cerebral palsy; complex seizure disorder; mental handicaps
Affiliations: Concerned Parents of the Handicapped -- President; Parents and Professionals Advocating for the Handicapped -- President; TOUCH (To Our Understanding of Children with Handicaps); First Steps ICC 99-457; Governor's Planning Council for Persons with Disabilities
Care Facility: Deaconess Hospital -- Evansville, IN
Skills and Interests: Developed training program for parents; parent-to-parent support
Experience: Public speaking; leading training for health care providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments

Pat Rieger
2110 East 65th Street
Indianapolis, IN 46220
317 257-6598

Child's Disabilities: Duchenne muscular dystrophy
Affiliations: Muscular Dystrophy Association Parent Support Group -- Founder
Care Facility: Methodist Children's Hospital -- Indianapolis, IN
Skills and Interests: Parent-to-parent support
Experience: Methodist Children's Hospital -- Parent Advisory Board Member; public speaking; leading training for health care providers/teachers; starting or maintaining support groups

Rosalie N. Ruffin-Black
5830 Laurel Hall Drive
Indianapolis, IN 46226
317 545-5788
317 257-8683

Child's Disabilities: Cerebral palsy (03/20/80)
Affiliations: Indiana State Board of Health -- Subcommittee Member, Program for Children with Special Health Care Needs; United Cerebral Palsy -- Annual Planning Committee; First Steps; Task Force Member
Care Facility: Methodist Cerebral Palsy Clinic -- Indianapolis, IN
Skills and Interests: Early intervention; recreation
Experience: Starting or maintaining parent/family support groups; public speaking
Related Employment: Secretary, Indiana Parent Information Network

Katherine Ann Weaver
29089 U.W. Highway 20 West
Elkhart, IN 46514
219 293-7741 (8 a.m. to 2 p.m.)
219 295-5649

Child's Disabilities: Cystic fibrosis; asthma; allergies (10/16/76)
Affiliations: The Cystic Fibrosis Council; Families Uniting; Cystic Fibrosis Council of Elkhart County
Care Facility: Elkhart General Hospital -- Elkhart, IN
Skills and Interests: Financing; Medicaid and SSI limitations; educational and support services
Experience: Testifying on chronic illness for revision of Indiana's Rule S-1 on educational

services; working on committee to implement Over 21 program for cystic fibrosis patients; starting or maintaining parent/family support groups; public speaking; training parents, health care providers, and teachers; promoting legislation
Related Employment: Coordinator, Cystic Fibrosis Council of Elkhart County

Carol Whetsel
442 East State Street
Pendleton, IN 46064
317 778-4192

Child's Disabilities: Cystic fibrosis (05/31/80)
Affiliations: Cystic Fibrosis Parent Support Group
Care Facility: Riley Hospital for Children -- Indianapolis, IN
Skills and Interests: Parent-to-parent support; organized family support conference
Experience: Public speaking; leading training for health care providers/teachers; promoting legislation; starting or maintaining support groups; Riley Hospital for Children -- Parent Advisory Board

Dorie Winquist
57138 Westlake Drive
Middlebury, IN 46540
219 825-7347

Child's Disabilities: Interrupted aortic arch; DiGeorge syndrome; tracheomalacia; respiratory dependent (04/05/88)
Care Facility: Riley Children's Hospital -- Indianapolis, IN
Skills and Interests: Parent networking; home care for technology dependent children
Experience: Promoting legislation
Related Employment: R.N., Elkhart General Hospital

IOWA

Julie Beckett
4555 Westchester Drive, N.E., Unit D
Cedar Rapids, IA 52402
319 356-4294
319 395-7349

Child's Disabilities: Post encephalitis; ventilator assistance (03/09/78)
Affiliations: SKIP of Iowa -- Director; Birth to Three Parent Network -- Coordinator
Care Facility: St. Luke's Hospital -- Cedar Rapids, IA
Skills and Interests: Financing for chidlren with special health care needs; developing community-based, family-centered care programs; developing care coordination systems
Experience: Serving on the Bio-Medical Ethics Advisory Committee for the U.S. Congress; assisted in developing *Iowa Health Care Guidelines for Families*; Department of Health and Human Services, Task Force on Technology Dependent Children -- Vice Chairperson; public speaking; leading training for health care providers and teachers; promoting legislation; starting or maintaining parent/family support groups; Iowa Child Health Speciality Clinics, University of Iowa -- Program Assistant; Resource Parent Project, CAPP, Federation for Children with Special Needs -- Consultant
Related Employment: Independent consultant to state governments on developing waivers and programs in early intervention

Craig and Ruth Bolinger
RR 1 Box 170
Creston, IA 50801
515 782-2917

Child's Disabilities: Hydrocephalus; bilateral shunt; neuromuscular involvement; visual impairment/optic atrophy; hyperverbalism; developmental delay (03/19/83)
Affiliations: Iowa Parents of Visually Impaired Children -- Board Member; Council for Exceptional Children; ACCH; American Council on Rural Special Education; National Association/Iowa Education of Young Children; National Hydrocephalus Foundation; National Association for Parents of Visually Impaired Children; Creston Pilot Parents; Iowa Governor's Planning Council for Developmental Disabilities -- Vice Chairperson
Care Facility: Iowa Methodist Medical Center; University of Iowa Hospital Schools & Child Health Specialty Clinics
Skills and Interests: Rural delivery; parent education and training; training for rural providers specific to farm family needs and financing for self-employed operations; legislation supporting financial and situational goals of farm families with children who have special needs
Experience: Designed and implemented

lay/parent home visitor program for regional educational delivery systems; developed and implemented specialized trainings regarding family-centered care on the farm and the impact on family finances; served in lay/health visitor program (a hospital to community based program) called Friends of New Parents; Parent-Educator Coordinator for regional education delivery system; *Iowa Exceptional Parents Center -- outreach/trainer; worked on the P.L. 99-457 Sub-Committee on Case Management and IFSP; starting or maintaining parent/family support groups; public speaking; training parents, health care providers, or teachers; promoting legislation
Related Employment: Freelance consultant for training and advocacy; Program Assistant, Iowa State University Extension Service

Deb House Deere
RR 3 Box 9
Ottumwa, IA 52501
515 683-3823
515 684-5114

Children's Disabilities: Twins -- cerebral palsy (1979)
Care Facility: University of Iowa Hospital -- Iowa City, IA
Skills and Interests: Working directly with parents; education for children with disabilities; parent/professional communication
Experience: Public speaking; conducting training sessions for health care providers/teachers; promoting legislation; starting or maintaining support groups; Specialized Child Health Committee of the University of Iowa Hospital -- Parent Representative; working with the Education Department to enhance communication between parents and professionals and provide information and resources
Related Employment: Community Service Coordinator, Early Intervention Services, Arca Education Agency

Larry and Lyn Hafner
29 Wolfbrook Circle
Iowa City, IA 52240
319-351-0648

Child's Disabilities: Static nonprogressive post-infectious encephalopathy with hypotonia; seizure disorder; developmental delay; gastrostomy; history of feeding intolerance (10/02/84)
Affiliations: ARC
Care Facility: University of Iowa Hospitals and Clinics -- Iowa City, IA
Skills and Interests: Parent-to-parent support; home care needs and programs; lobbying for Iowa Bill of Rights
Experience: Public speaking; conducting training sessions for health care providers/teachers; promoting legislation; starting or maintaining support groups; working with state health department on Model Title XIX Waiver Program

Denny Hoyt
1024 Curtis
Ames, IA 50010
515 233-1547
515 233-4104

Child's Disabilities: Lissencephaly; G-tube; respiratory difficulties
Affiliations: ACCH; ARC; TASH; Birth to Three Network
Care Facility: Mary Geeley Hosptial; University of Iowa Hospital and Clinics
Skills and Interests: Respite care; health care financing; early intervention; fathers' issues; child care; community organizations; parent leadership development; spirituality
Experience: Iowa Council for Early Intervention Services; Iowa Planning for Developmental Disabilities; assisted in developing statewide parent consultant network for CHSC; family support consultant for Iowa Home Care Monitoring Program; worked with local parents to develop integrated summer day care program for children with special needs; starting or maintaining parent/family support groups; public speaking; training parents, health care providers, and teachers; promoting legislation
Related Employment: Family support consultant, University of Iowa Child Health Specialty Clinic

Harry and Gail Posner Karp
4721 Belle Avenue
Davenport, IA 52807
319 355-8858

Child's Disabilities: Autism (06/06/83)
Affiliations: Autism Society of Iowa -- Parent Advocacy Network Director; Quad-City Society for Autistic Children; Autism Society of America

-- Information and Referral Committee; Special Needs and Parent Support (SNAPS) -- Founder; Scott County Association for Retarded Citizens; Community Programs Scholarship Fund -- Founder; Iowa Governor's Task Force on Autism
Care Facility: Child Psychiatry, University of Iowa -- Iowa City, IA
Experience: Iowa ICC -- Corresponding Member; starting or maintaining parent/family support groups; public speaking; training parents and teachers; promoting legislation
Related Employment: Consultant, Program Development, Hospital School for Developmental Disabilities, University of Iowa

Carla Lawson
1602 10th Avenue, N.
P.O. Box 791
Fort Dodge, IA 50501
515 576-5870
515 576-1877

Children's Disabilities: Twins -- Werdnig-Hoffmann disease (06/25/65 to 1983 and 06/25/65 to 1989)
Affiliations: Iowa Pilot Parents -- Executive Director; *Iowa Exceptional Parents Center; Iowa Self-Help Clearinghouse; Iowa Parent to Parent Conference; Iowa Registry for Special Needs Conference
Care Facility: University Hospital & Clinics -- Iowa City, IA; Iowa Methodist Medical Center and Iowa Lutheran Hospital -- Des Moines, IA
Skills and Interests: Talking with parents of children with special needs; parent education and training concerning law and health care system; working with health and education professionals; communication, stress, and coping; genealogy; writing; working with church senior high youth
Experience: Parent-to-parent (Pilot Parents) support; public speaking; professional education and inservice; promoting legislation; starting or maintaining support groups; management of Parent Center; served on variety of local, state, regional, and national boards/committees; previous foster parent; adoptive parent; assisted in writing the publication *Iowa Health Care Guidelines for Families*
Related Employment: Executive Director, Iowa Pilot Parents, Inc.

Jan Mackey
8217 Sutton Drive
Urbandale, IA 50322
515 280-1407
515 276-2544

Child's Disabilities: Down syndrome (04/12/88)
Affiliations: Birth to Three Network; Heartland Area Education Agency (AEA) -- Parent Educator Project; Up with Downs -- Family Support Group
Care Facility: Mercy Pediatrics -- Des Moines, IA
Skills and Interests: Respite care; early intervention; preventable birth defects
Experience: Working with Des Moines school system on early childhood issues; starting or maintaining parent/family support groups; public speaking
Related Employment: Parent Educator, Family Ecology Center; Parent Coordinator, Heartland AEA

Jule Reynolds
Special Care Parents
1922 East 12th Street
Des Moines, IA 50316
515 263-9247

Child's Disabilities: Cerebral palsy; premature seizure disorder; respiratory disorder
Affiliations: Special Care Parents -- Chairperson; *Iowa Exceptional Parents Center
Care Facility: Iowa Methodist Medical Center and Blank Children's Hospital -- Des Moines, IA
Experience: Department of Education -- Parent Consultant and Technical Assistance Facilitator; public speaking; leading training for health care providers/teachers; starting or maintaining support groups; working with state health departments

Nancy Thompson
Route 1
Ft. Dodge, IA 50501
515 359-2360

Child's Disabilities: Hypertelorism-hypospadius syndrome; mental retardation; fragile health; hearing impairment; illiostomy urinary diversion
Affiliations: National Apostolate for Ministry with Mentally Retarded Persons; Iowa Governor's Developmental Disabilities Council Employment

Planning Group; Renewed Services Delivery System
Care Facility: University of Minnesota -- Minneapolis, MN
Skills and Interests: Transition; parent/professional collaboration; ministry; employment; full participation in the community; self-advocacy
Experience: Steering committees/advisory groups related to education, employment, ministry, transition, parent/professional collaboration, and health care issues; conducting workshops on those and other topics for parents and service professionals; promoting legislation and systems change
Related Employment: Consultant for regional, state, and national organizations; Director, Coalition For Ministry With Persons Who Have Disabilities, Diocese of Sioux City, IA

KANSAS

Kathy Johnson
4445 Northwest 52nd Terrace
Topeka, KS 66618
913 273-6343
913 246-2114

Child's Disabilities: Cerebral palsy
Affiliations: *Families Together, Inc. -- Parent Center Resource Coordinator; Preschool Advisory Council
Care Facility: Kansas University Medical Center -- Kansas City, KS
Skills and Interests: Parent assistance in educational matters and resource coordination; parent training; family enrichment weekends
Experience: Citizens Advisory Council on Preschool Handicapped; Families Together Family Enrichment Weekend -- Adult Resources Coordinator; public speaking; leading training for health care providers and teachers; promoting legislation; starting or maintaining parent/family support groups; working with state health department as consultant on SPRANS grant and on task force for interagency agreement
Related Employment: Resource coordinator, *Families Together, Inc.; Special education teacher

June H. Rouse
8445 Linden Lane
Prairie VIllage, KS 66207
913 648-6464

Children's Disabilities: Seizure disorder; cerebral palsy (11/08/78 to 12/29/80); Down syndrome (05/03/82)
Affiliations: Down Syndrome Guild of Greater Kansas City -- Co-founder, Board Member, former President; Down Syndrome Clinic, Children's Mercy Hospital -- Parent Representative/Coordinator
Care Facility: Private physicians
Skills and Interests: Parent contact at time of diagnosis; parent staffing at hospitals
Experience: Integration Coordinating Council -- keeping track of various inclusionary programs in school district; Advisory Council Parent Resource Center, Shawnee Mission School District; starting or maintaining parent/family support groups; public speaking; training parents, health care providers, and teachers; volunteer

Shannon Scholler
602 South Chantanqua
Wichita, KS 67211
316 689-8849

Child's Disabilities: Central alveolar hypoventilation (Ondine's Curse); prematurity; ventilator dependent at night (04/20/82)
Affiliations: Parents and Friends of Special Care Infants; Parents of Children with Congenital Central Hypoventilation Syndrome
Care Facility: Scottish Rite Children's Hospital -- Atlanta, GA; Joseph's Hospital -- Wichita, KS
Skills and Interests: Broad networking of parent groups; equal access to information; categorical loopholes that eliminate children from service; insurance
Experience: Designing workshops for parents of children with chronic conditions in coping with stresses of family life and recurrent hospitalizations; helping to start family resource library; working with social work departments of local hospitals for referrals to support groups for parents of infants with special needs; starting or maintaining parent/family support groups; public speaking; training parents
Related Employment: Preschool teacher

KENTUCKY

Beverly Branscum
12201 U.S. 42
Walton, KY 41094
606 485-6145

Child's Disabilities: Camptomelia (rare form of dwarfism) (06/01/83)
Care Facility: Children's Hospital Medical Center -- Cincinnati, OH; Johns Hopkins Hospital -- Baltimore, MD
Skills and Interests: Education of officials regarding insurance issues and community-based waivers; financing home care; educational issues
Experience: Promoting legislation for community-based waivers; *Kentucky Special Parent Involvement Network (SPIN) -- Regional Coordinator

Gayle B. Brown
249 St. Margaret Drive
Lexington, KY 40502
606 269-5707

Child's Disabilities: Spina bifida (11/07/84)
Affiliations: Spina Bifida Association -- Outreach Volunteer; NeoLife (support for families with a baby in the NICU); Parent Share Group (support group for mothers of children with disabilities)
Care Facility: University of Kentucky Hospital -- Lexington, KY
Skills and Interests: Adoption information for infants and children with Spina bifida; 504 regulations in public schools
Experience: Outreach work for the Spina Bifida Association at UK Hospital, Shriners Hospital, and the Commission for Handicapped Children; starting or maintaining parent/family support groups; training parents, health care providers, and teachers

Donna M. Connell
109 Circle Drive
Morehead, KY 40351
606 783-1095
606 784-7580

Child's Disabilities: MRDD; behavior disorder; seizures; emotional disturbance; severe depression (02/04/77)
Affiliations: Kentucky Families as Allies -- Parent Coordinator
Care Facility: Child Evaluation Center and Ten Broeck Hospital -- Louisville, KY
Skills and Interests: Needs of children with behavior disorders; adolescent mental health
Experience: Kentucky Respite Task Force; Kentucky Coalition for People with Handicaps (parent support); starting or maintaining parent/family support groups; public speaking; training parents, health care providers, or teachers; promoting legislation
Related Employment: Parent Coordinator, Kentucky Families as Allies

Jean Isaacs
640 Maxwelton Court
Lexington, KY 40508
606 255-9951
606 252-6609

Child's Disabilities: Cerebral palsy (05/20/84)
Affiliations: Alliance for Technology Access; Kentucky Assistive Technology Service Network
Care Facility: Central Baptist, Cardinal Hill, and W.K. Medical Center -- Lexington, KY; Frazier Rehabiliation -- Louisville, KY
Skills and Interests: Assistive technology; funding
Experience: Smart Agency -- Advisory Board; Fayette County Schools -- Technology for Special Education Task Force; Interdisciplinary Human Development Institute (UAP); Mothers of Special Needs; starting or maintaining parent/family support groups; public speaking; training parents, health care providers, and teachers; promoting legislation
Related Employment: Director of Education and Technical Assistence, Bluegrass Technology Center

Lavonna King
5974 Rich Pond Road
Bowling Green, KY 42104
502 843-6191

Children's Disabilities: Two children with cerebral palsy; multiple handicaps (02/17/75 and 07/16/81)
Affiliations: Kentucky Commission for Handicapped Children
Care Facility: Jewish Hospital -- Louisville, KY
Skills and Interests: Education needs of children with special needs; parent-to-parent support
Experience: Kentucky Commission for Handicapped Children -- past Chairperson; United Cerebral Palsy Association, South Central

Kentucky -- past Chairperson; public speaking; promoting legislation

Beverly Parks
2109 Sage Road
Lexington, KY 40504
606 277-3698

Child's Disabilities: Cri-du-chat syndrome (06/03/86)
Affiliations: Mom's Share Group -- Contact person; 5p Society
Care Facility: Private physician; Shriners Hospital -- Lexington, LA
Skills and Interests: Parent-to-parent support; access to information
Experience: Starting or maintaining parent/family support groups

LOUISIANA

Dell B. Amos
7500 Primroses Drive
New Orleans, LA 70126
504 896-9287
504 242-8338

Child's Disabilities: Mild mental retardation (12/05/68)
Affiliations: Children's Hospital -- Parent Resource Developer
Skills and Interests: Transition (adolescent through adult)
Experience: Infant and Toddler Pilot Program -- Parent liaison; starting and maintaining parent/family support groups; public speaking; training parents
Related Employment: Parent Resource Developer, Children's Hospital

Ronald and Rena Breaux
Route 8, Box 1737
Sailfish Drive
Lake Charles, LA 70605
318 474-5727

Child's Disabilities: Rett syndrome (03/23/83)
Affiliations: International Rett Syndrome Foundation; Louisiana Rett Syndrome Foundation -- Co-directors; Louisiana Cerebral Palsy Foundation; Pearl Watson Parents Involvement Group -- Co-directors; Community Based Services Project Parents Support Group -- Co-directors; Council for Exceptional Children -- Special Education Parents of the Year; Parents Advisory Committee -- Board Members; State Parents Advisory Committee -- Board Members
Care Facility: Handicapped Children's Services, Calcasieu Parish Health Unit, St. Patrick's -- Lake Charles, LA
Skills and Interests: Lobbying for legislation for children with disabilities; better education (3-year evaluation); respite care; greater parent involvement in schools; increasing parents' knowledge of rights; P.L. 99-457; financial support; emotional support; school therapy
Experience: Community Based Project Services -- Board Member; surrogate parents for IEP's; starting or maintaining parent/family support groups; public speaking; training parents, health care providers, and teachers; promoting legislation
Related Employment: Co-directors, Louisiana Rett Syndrome Foundation

Denise Briley
P.O. Box 712
Vinton, LA 70668
318 589-3127

Child's Disabilities: Cerebral palsy; congential cytomegalovirus (CMV) (12/09/83)
Affiliations: Community Based Services (Handicapped Childrens Service) -- Parent support group; LACAN
Care Facility: West Cal-Cam Hospital and Sulphur Pediatric Clinic -- Sulphur, LA
Skills and Interests: Improving education and services for children with disabilities
Experience: Surrogate parent for children who attend school, but who are in an institution (to see that their education needs are met); Community and Family Support Advisory Committee; Task Force for the Implementation of Community and Family Support in Louisiana; public speaking; training parents; promoting legislation
Related Employment: Volunteer in advocacy field

Beverly Butler
3027 Alex Kornman Boulevard
Harvey, LA 70058
504 896-9287
504 341-0757

Child's Disabilities: Spina bifida (01/04/83)
Affiliations: Spina Bifida Organization

Care Facility: HCP at Children's Hospital -- New Orleans, LA
Experience: Starting or maintaining parent/family support groups; public speaking
Related Employment: Parent Liaison, Metro Family Centered Services, Children's Hospital

Mary Lou Cutrera
2426 Silverest Avenue
Baton Rouge, LA 70816
504 923-0305

Child's Disabilities: Tetralogy of Fallot (congenital heart defect)
Affiliations: Congenital Heart Information Program, Inc. -- Secretary; Mended Hearts, Inc. -- Editorial Board Member; HEARTBEAT (journal)
Care Facility: Southern Baptist Hospital -- New Orleans, LA
Skills and Interests: Parent support and information; publication of materials of interest to families of children with heart disease; writing articles; increasing public awareness
Experience: Public speaking; starting or maintaining support groups
Related Employment: English Instructor, Louisiana State University

Lorie Emmons
8207 Burning Tree
Shreveport, LA 71108
318 688-0849
318 688-0849

Child's Disabilities: Hydrocephalus; infantile spasms; cerebral palsy; developmental delay (04/04/88)
Affiliations: H.E.L.P. (Help for Exceptionally Loving Parents)
Care Facility: Schumpert Medical Center -- Shreveport, LA
Experience: Fundraising for special needs; Caddo-Bossier ARC; Access -- Case Manager Program

Tim C. and Laura Fitzgerald
12086 Ellerbe Road
Shreveport, LA 71115

Child's Disabilities: Post-encephalitis; cerebral palsy; visual impairment; developmental delay (01/05/86)
Affiliations: Help for Exceptionally Loving Parents (H.E.L.P.); Caddo-Bossier ARC -- Board of Directors
Care Facility: Schumpert Medical Center -- Shreveport, LA; private physician
Skills and Interests: Early intervention
Experience: Starting or maintaining parent/family support groups; public speaking; promoting legislation; Tim -- Co-chairman of the State Interagency Coordinating Council for P.L. 99-457

Rose Anne Gilbert
412 Colonial Club Drive
Harahan, LA 70123
504 734-7736
504 737-3149

Child's Disabilities: Asthma; speech impairment; visual impairment (11/80)
Affiliations: CATER (Center for Adaptive Technology and Educational Resources); Project PROMPT
Care Facility: Rothschild Pediatric Clinic
Experience: Maintaining parent/family support groups; public speaking; training parents, health care providers, and teachers
Related Employment: Project Coordinator, Project PROMPT

Barry and Mary Ellen McCain Hoffman
4451 Gilbert
Shreveport, LA 71106
318 865-7026
318 869-1111

Child's Disabilities: Limbless; scoliosis; kyphosis (06/06/78)
Affiliations: Help Exceptionally Loving Parents (H.E.L.P.)
Care Facility: Thompson's Children's Hospital -- Chattanooga, TN; Gilette Children's Hospital -- St. Paul, MN; Highland Hospital -- Shreveport, LA
Experience: Worked with the education department on the Special Education Advisory Council; public speaking

Peggy P. LeBlanc
5105 Tartan Drive
Metairie, LA 7003
504 896-9287
504 889-0390

Child's Disabilities: Cystic fibrosis (03/04/71)
Affiliations: Cystic Fibrosis Foundation --

Louisiana Chapter Board Member; Tulane Pediatric Pulmonary Clinic -- Advisory Committee Parent Member; Education & Support Program, Children's Hospital -- Board Member
Care Facility: Children's Hospital and Tulane Pediatric Pulmonary Clinic -- New Orleans, LA
Skills and Interests: Parent/professional collaboration; parent-to-parent support; parent education
Experience: State Advisory Council Member; Ventilator Assisted Care Program; Tulane Pediatric Pulmonary Center -- Advisory Board Member; Children's Hospital -- Ethics Committee Member; Regional Team for Legislative Lobbying; starting or maintaining parent/family support groups; public speaking; training parents, health care providers, and teachers; promoting legislation
Related Employment: Parent Coordinator, National MCH Resource Center, Children's Hospital

Shelly LeBlanc
8930 Brookwood, #A-9
Shreveport, LA 71118
318 688-4209

Child's Disabilities: Infantile seizures; gastroesophageal reflux (10/27/86)
Affiliations: Caddo Advocacy Program (CAP)
Care Facility: Willis Knighton Medical Center and Handicapped Children's Clinic -- Shreveport, LA; private physician
Experience: Attended Public Hearing on P.L. 99-457 and seminar on "How to Access Services in Your Community"
Related Employment: In training as respiratory therapist

Nancy C. Samrow
1424 North Sibley Street
Metairie, LA 70003
504 467-4706

Child's Disabilities: Spina bifida; higher lumbar meningomyelocele; hydrocephalus (01/19/81)
Affiliations: Greater New Orleans Spina Bifida Association -- Camp Committee; Education and Support Program; Children's Hospital -- Parent Link (a parent visitation program)
Care Facility: Children's Hospital -- New Orleans, LA
Skills and Interests: Financing; fundraising; legislation; early intervention; parent-to-parent support
Experience: Participating in the Education and Support Program, Children's Hospital; writing editorials; starting or maintaining parent/family support groups; public speaking; training parents, health care providers, or teachers; promoting legislation

Lucienne D. Siragusa
#10 Carlsbad
Kenner, LA 70065
504 467-3918

Child's Disabilities: Bilateral cleft lip and palate
Affiliations: Organization for Parents of Cleft Children (parent support group) -- President; Education Support Program, Children's Hospital of New Orleans; National Cleft Lip and Palate Association -- Secretary, National Board
Care Facility: Southern Baptist Hospital and Children's Hospital -- New Orleans, LA
Skills and Interests: Public education about clefts; care for a person with a cleft
Experience: Public speaking; conducting training sessions for health care providers; training on starting or maintaining support groups; serving on cleft team at local hospital; visiting parents of newborns with cleft lip and/or palate; representing local support group
Related Employment: Art teacher

Larry and Julie Walker
1306 Peach Street
Vidalia, LA 71373
318 336-7336

Child's Disabilities: High quadriplegia (C-O, C-1) and ventilator dependence from a bike/auto accident (06/25/78)
Affiliations: SKIP
Care Facility: Children's Hospital -- New Orleans, LA
Skills and Interests: Financing for middle income families; insurance with low cap; regular education with support services
Experience: Public speaking; training health care providers, teachers' aides, and grandparents

Beth Witt
302 Short Leaf
Haughton, LA 71037
318 631-5110
318 949-3492

Child's Disabilities: Severe/profound brain damage; mental handicaps (birth injury) (12/04/72)
Affiliations: ARC; Northwest State School Parent Group -- former Vice President and Board Member; Council for Exceptional Children/Local chapter -- former Officer; Division of Mental Retardation -- former State Vice President and State President
Care Facility: Louisiana State University Medical Center -- Shreveport, LA
Experience: Providing assessment, support, and consultation to parents, children, and teachers; teaching preschool children with disabilities; starting or maintaining parent/family support groups; public speaking; training parents and teachers; promoting legislation; published materials for preschool children with disabilities
Related Employment: Education Assessment Teacher and Preschool Specialist, Caddo Parish Special Education Center

MAINE

Jane Morrison Bubar
31 Roosevelt Avenue
Waterville, ME 04901
207 289-4200
207 872-8392

Child's Disabilities: Hydrocephalus; cerebral palsy; left hemiplegia; visual impairment; seizure disorder (01/17/76)
Affiliations: United Cerebral Palsy of Northeast Maine -- Telethon Publicity; Association for Young Children with Special Needs/Maine; Very Special Arts/Maine -- Board Member; *Special Needs Parent Information Network (SPIN)
Care Facility: Mid-Maine Medical Center -- Waterville, ME
Skills and Interests: Public information/education (general); parent and consumer empowerment; interagency cooperation/communication; family value base
Experience: Public speaking; conducting training sessions for health care providers, teachers, and governing boards; promoting legislation; working on inter-departmental state committees -- reviewing regulations, writing/editing newsletter, and as trainer in media relations
Related Employment: Acting Director of Information, Maine Department of Mental Health and Mental Retardation

Caroline C. Hyde
189 Sweetser Road
Pownal, ME 04069
207 688-2203

Child's Disabilities: Mental retardation
Affiliations: *Special Needs Parent Information Network (SPIN); Main Parent Federation -- Board Member; Commission on Transition (COT) -- Parent Representative
Skills and Interests: Developing family-centered comprehensive service delivery system for children with special needs from birth to age five
Experience: Promoting legislation; starting or maintaining support groups; working with Maine's Lead Agency for 99-457
Related Employment: Audiologist
Languages other than English: French

Kevin O'Sullivan
RR 1, Box 1628
Bowdoinham, ME 04008
207 623-6647
207 666-3222

Child's Disabilities: Down syndrome (08/16/89)
Affiliations: Birth to Three Network; State Interagency Coordinating Council -- Treasurer; Parent Advisory Council on Early Intervention -- Chairman
Care Facility: Private physician
Skills and Interests: Early intervention; parent involvement in policymaking
Experience: State ICC -- Finance Subcommittee Chairman; starting or maintaining parent/family support groups; public speaking

Sherry S. Pierce
11 Leach Road
P.O. Box 273
Fryeburg, ME 04037
207 935-2092
207 935-3616

Child's Disabilities: Hypsarrhythmia; mixed seizure disorder

Care Facility: Massachusetts General Hospital -- Boston, MA
Skills and Interests: Respite care; parent/professional collaboration; parent advocacy
Experience: Governor's Advisory Council for the Bureau of Children with Special Needs -- former Member; public speaking; promoting legislation; working with state health departments
Languages other than English: French

MARYLAND

David R. Buckholtz and
Karen Crawley-Buckholtz
2956 Rose Crown Circle
Pasadena, MD 21122
301 437-6614

Child's Disabilities: Twins -- Tracheomalacia; subglottic stenosis; bronchopulmonary dysplasia; cerebral palsy; developmental delay; Bronchopulmonary dysplasia; cerebral palsy; obstructive sleep apnea
Affiliations: Hand in Hand, Inc. -- Co-Founders, Karen -- Executive Director, David -- Public Awareness Coordinator; SKIP -- Karen -- President; Maryland Developmental Disabilities Council -- David; Governor's Advisory Board for Handicapped Individuals -- Karen
Care Facility: St. Agnes Hospital and Johns Hopkins Hospital -- Baltimore, MD
Skills and Interests: Helping parents access services; educating professionals about parent/family needs
Experience: Public speaking; Karen -- parent trainer/instructor; promoting legislation; starting or maintaining parent/family support groups; conducting training sessions for health care providers/teachers; Karen -- training in hospice counseling and finishing a degree in Child Psychology
Related Employment: Karen -- Crisis intervention counselor
Languages other than English: Karen -- Sign language

William and Terri Cameron
14 Vienna Court
Frederick, MD 21702
301 695-8769

Children's Disabilities: Rubinstein-Taybi syndrome (11/10/77); Down syndrome (10/04/84); Fetal alcohol syndrome (01/02/88)
Affiliations: Rubinstein-Taybi Parent Group; FRIENDS (Family Resource Information and Education Network for Down Syndrome); Foster Care Support Group
Care Facility: Children's Hospital National Medical Center -- Washington, DC
Skills and Interests: Early intervention
Experience: Maryland Coalition for Integrated Education; Maryland Infants and Toddlers Program; starting or maintaining parent/family support groups

Sheila K. Collins
5301 Manorfield Road
Rockville, MD 20853-2512
301 460-7588

Child's Disabilities: Williams syndrome (11/18/83)
Affiliations: Williams Syndrome Association -- Regional Educational Director; Maryland's Partners in Planning for P.L. 99-457 (ICC) -- Co-chairperson; Montgomery County Special Needs Preschool Parent Group -- Founding Member
Care Facility: Bethesda Naval Hospital -- Bethesda, MD
Skills and Interests: Early intervention
Experience: Serving on the State's Interagency Coordinating Council; starting or maintaining parent/family support groups; public speaking; previously worked as a nurse educator

Katherine and James Cooper
522 Idlewild Road
Bel Air, MD 21014
301 838-9015

Child's Disabilities: Mental retardation (extra marker chromosome) (07/23/85)
Affiliations: ARC/Harford County -- Parent Support Group
Care Facility: Private physician; Harford County Health Department
Experience: Harford County ICC -- Chairperson; public speaking
Related Employment: Part-time English teacher, Harford Community College

Pat Downey
4137 #2 Falcon Place
Waldorf, MD 20603
301 843-3185

Child's Disabilities: I-cell disease; mucolipdosis II (deceased)
Care Facility: Lutheran General -- Parkridge, IL
Skills and Interests: Writing
Experience: Author of two booklets: *Let's Play with Our Children* and *New Directions for Exceptional Parenting* (both available from ACCH); public speaking; leading training for health providers and teachers; promoting legislation; starting or maintaining support groups
Related Employment: Freelance writer

Dorothy and Walter Dustmann
2659 Ebony Road
Baltimore, MD 21234

Child's Disabilities: 49XXXXY syndrome (02/01/85)
Affiliations: Intervention with Parents and Children Together, Inc.; PACT Family Support Group; Baltimore's Coalition for Integration in the School System; *The Parents' Place of Maryland, Inc.
Care Facility: Alfred I. du Pont Institute (downstate clinics); Georgetown Children's Clinic; Public Health (Sussex County)
Skills and Interests: Early intervention; family support care coordination
Experience: Served on Delaware's Interagency Coordinating Council for P.L. 99-457; serving on Baltimore City's ICC; starting or maintaining family support system; public speaking; educational support for families and teachers; promoting legislation
Related Employment: Dorothy -- Office Manager, *The Parents' Place of Maryland, Inc.

Ellen Feifarek
508 Hampton Lane
Towson, MD 21204
301 337-8899
301 583-7633

Child's Disabilities: Autism; Pervasive developmental disorder (09/05/85)
Affiliations: Autism Society of America/Baltimore Chesapeake Chapter -- Education Chairperson; Pervasive Developmental Disorders Mother Support Group -- Co-founder; Learning Disabilities Association of America
Care Facility: Private physician -- Lutherville, MD; White Oak Special School -- Parkville, MD
Skills and Interests: Improved education for children with autism and PDD through teacher training, parent education, early intervention, and comprehensive programming
Experience: Formation of summer program for preschoolers with PDD; advocating for improved educational services; Maryland State ICC for 99-457 -- Parent Representative; starting or maintaining parent/family support groups; public speaking; training health care providers and teachers
Related Employment: Adult psychiatrist

Mary Regina Grochmal
5444 Whitlock Road
Baltimore, MD 21229
301 744-1502

Children's Disabilities: Prematurity (developmental delay) (06/07/90); Cerebral palsy (10/89)
Affiliations: Specialized Foster Care Program
Care Facility: The Kennedy Institute -- Baltimore, MD
Experience: Starting or maintaining parent/family support groups; public speaking; training parents
Related Employment: Pediatric Nurse, St. Agnes Hospital -- Baltimore, MD

Ursula C. Guy
3132 Old Taneytown Road
Westminster, MD 21157
301 751-1242

Child's Disabilities: Batten disease (04/15/71)
Skills and Interests: Coordinating complex home care program for medically fragile child
Experience: Public speaking; involved with the Coordinating Center for Home and Community Care in Maryland
Related Employment: Nurse

Gail D. Johnson
7339 A Creed Court
Ft. Mead, MD 20755
301 672-3801

Child's Disabilities: Down syndrome; atrial septal defect (09/02/86)

Affiliations: Special Parent Information Network (SPIN); Special Education Advisory Council (SEAC); Zero to Three Hawaii -- Parent Representative, Central Directory and Flow Services Committees Member; Exceptional Family Member Program/Army (EFMP) Liaison; Assisting With Appropriate Rights in Education (AWARE) Governing Council; Project PO'OHALA (Statewide Family Forum)
Care Facility: Tripler Army Medical Center (Child Development Clinic) -- Honolulu, HI
Skills and Interests: Respite; early intervention; recreational activities; case management; IFSP's; mainstreaming in developmental centers and regular day care facilities; information and referral for parents of special children; parent support; establishing data base resources; educating para-professionals
Experience: Providing reference and resource information referral service through SPIN; public speaking; training health care providers, teachers, special education teachers, and students; advocating phoneline support; assisting and providing input for action steps and governing policies for Commission on Persons with Disabilities under the Department of Health; actively working with regional plans for state goals; opening doors in generic programs, services, and agencies to accommodate families of children with special needs

Helen Reisner
10606 Lorain Avenue
Silver Spring, MD 20901
301 681-9064

Child's Disabilities: Epilepsy; mental retardation
Affiliations: Epilepsy Foundation of America/National Capital Area; Association for Retarded Citizens/Montgomery County; ACCH; CIBA-GEIGY Speaker's Bureau
Care Facility: Georgetown University Hospital -- Washington, DC; University of Virginia Medical Center -- Charlottesville, VA
Skills and Interests: Fundraising; writing; speaking; parent-to-parent support; coalition building; filmmaking
Experience: Training and technical assistance for parents, health care providers, and educational professionals; coalition building; editor -- *Children with Epilepsy: A Parents' Guide* (1988, Woodbine House, Rockville, MD); executive producer -- *Just Like You & Me* (1990, State of the Art, Inc., Washington, DC)

Amita Sarin
8308 River Falls Drive
Potomac, MD 20854
301 299-5606

Child's Disabilities: Cerebral palsy; blindness; mental retardation (01/28/79)
Care Facility: Children's Hospital National Medical Center -- Washington, DC
Skills and Interests: Training health professionals about the needs of families; ethical issues in treatment
Experience: Children's Hospital National Medical Center -- Ethics Forum Member; public speaking; leading training for health providers/teachers; writing
Languages other than English: Hindi

Claudia Segal
977 Paulsboro Drive
Rockville, MD 20850
301 279-1276
301 762-4858

Child's Disabilities: Cerebral palsy; epilepsy; learning disabilities (09/20/76)
Affiliations: ARC/Montgomery County; ACCH; The *Parents' Place of Maryland, Inc. -- Board Member; Montgomery County ICC for Implementation of P.L. 99-457
Care Facility: Children's Hospital National Medical Center -- Washington, DC
Skills and Interests: Integrated school and child care settings; respite care
Experience: Designing training program to assist parents in choosing child care for children with special needs; starting or maintaining parent support/advocacy groups; public speaking; training parents, health care providers, or teachers; promoting legislation; serving on local ICC
Related Employment: Referral counselor, Special Needs Program, Child Care Connection

Karen Shannon
216 Newport Drive
Severna Park, MD 21146
301 522-7500
301 647-0164

Child's Disabilities: Ventilator dependence until 1987; hearing impairment (11/21/79)
Affiliations: SKIP -- Founder and National Executive Director; *The Parents' Place of

Maryland, Inc. -- Co-founder and Board Member; Children's Medical Service -- Parent Advisory Committee Member
Care Facility: Johns Hopkins Hospital -- Baltimore, MD; Children's Hospital of Philadelphia -- Philadelphia, PA; A. I. Dupont Institute -- Wilmington, DE
Skills and Interests: Developing educational materials for families and professionals caring for children dependent on technology; public awareness; care coordination
Experience: Designing case management training; developing family support programs; member of Maryland work group to develop guidelines for P.L. 99-457; awarded Congressional fellowship to work on Capitol Hill; public speaking; leading training for health care providers/teachers; promoting legislation; starting or maintaining support groups; working with state health and education departments
Related Employment: Family consultant to family-centered care programs, The Kennedy Institute, Department of Community Services

Josie Thomas
9404 Saybrook Avenue
Silver Spring, MD 20901
301 654-6549
301 589-6727

Child's Disabilities: Congenital cytomegalovirus; deafness; cerebral palsy; learning disability (12/29/80)
Affiliations: MCAHIC (Montgomery County Association for Hearing Impaired Children); ARC/Montgomery County; *The Parents' Place of Maryland, Inc. -- Co-founder and Board President; Children's Medical Services -- Parent Advisory Board Member
Care Facility: Kaiser Permanente -- Washington, DC
Skills and Interests: Parent-to-parent support; providing inservices for teachers in early intervention; foster care; adoption of children with special needs
Experience: Starting or maintaining parent/family support groups; public speaking; training parents and teachers; establishing statewide parent organizations
Related Employment: Family Networking Coordinator, ACCH
Languages other than English: French; Spanish; Sign language

MASSACHUSETTS

Betsy Anderson
11 Davis Avenue
Brookline, MA 02146
617 482-2915
617 566-5998

Child's Disabilities: Spina bifida
Affiliations: *Federation for Children with Special Needs; Massachusetts Spina Bifida Association; ACCH -- former Board Member
Skills and Interests: Parent/professional collaboration; family-centered programs; parent training in P.L. 94-142; health care financing
Experience: Boston Children's Hospital -- Parent Advisory Committee; New England Regional Genetics Group -- Consumer Concerns Committee Chair; Congressional Committee on Health Care Financing for Technology Dependent Children; public speaking; leading training for health care providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments
Related Employment: Director of Health Issues, *Federation for Children with Special Needs; Director, CAPP Project (Collaboration Among Parents and Health Professionals)

Priscilla Bradway
18 Chandler Circle
Andover, MA 01810
617 475-0902

Child's Disabilities: Complete, unilateral cleft lip and palate; Type III hemifacial microsomia
Affiliations: Prescription Parents; The Foundation for Faces of Children -- Founding Member
Care Facility: The Children's Hospital -- Boston, MA
Skills and Interests: Parent support; support for brothers and sisters; workshops for teachers
Experience: Boston Children's Hospital -- Parent Advisory Committee; public speaking; conducting training for health care providers/teachers; starting or maintaining support groups
Related Employment: Early Childhood Education, M.A.T.

Betty Burton
52 Edgell Street
Gardner, MA 01440
617 632-7783

Child's Disabilities: Toxoplasmosis
Affiliations: Toxoplasmosis Foundation -- Founder
Care Facility: University of Massachusetts Medical Center -- Worcester, MA; Massachusetts Eye and Ear Infirmary and Massachusetts General Hospital -- Boston, MA
Skills and Interests: Parent education; parent-to-parent support group organizer; early intervention
Experience: Public speaking; leading training for health care providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments

Charles and Marilyn Fiske
70 Sewall Avenue
Brookline, MA 02146
617 566-3430

Child's Disabilities: Organ transplant
Affiliations: The Family Inn -- Founder; New England Organ Bank
Skills and Interests: Promoting legislation; developing housing for families of hospitalized children
Experience: Starting The Family Inn (a house for families to stay in while their children await organ transplants); public speaking; leading training for health care providers/teachers; starting or maintaining support groups; working with state and federal health departments

Linda Fox
6 Summer Street
Sandwich, MA 02563
508 888-6600

Child's Disabilities: Twins -- one with Spina bifida; diaphragmatic hernia (03/20/84)
Affiliations: Birth to Three Network; Interagency Coordinating Council for Early Intervention -- Parent Representative
Care Facility: Boston Children's Hospital -- Boston, MA
Skills and Interests: Early intervention
Experience: Working to establish Parent Network in Massachusetts; starting or maintaining parent/family support groups

Lynne and Thomas Murphy
20 Hamlet Street
Lawrence, MA 01843
508 683-1475

Child's Disabilities: Neurofibromatosis (05/19/78)
Affiliations: N7/Massachusetts Chapter -- Merrimack Valley Council Directors
Care Facility: Private physician -- Andover, MA; Children's Hospital -- Boston, MA
Skills and Interests: Children's support groups (to help them better understand, at their own level, their illness)
Experience: Starting or maintaining parent/family support groups; public speaking; training teachers
Related Employment: Diagnostic tester, Lawrence School Department
Languages other than English: Spanish

Barbara Popper
31 Wilshire Park
Needham, MA 02192
617 444-3877

Child's Disabilities: Paralysis of facial nerve
Affiliations: Children in Hospitals -- President
Skills and Interests: Support for families in hospitals; psychosocial policies and programs in hospitals; parent/professional collaboration at state level
Experience: Boston Children's Hospital -- Parent Advisory Board Member; developed *Consumer Directory of Hospital Policies in Massachusetts*; public speaking; leading training for health care providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments

Amy Robinson
45 Warren Street
Newton, MA 02159
617 527-7608

Child's Disabilities: Developmental delay; agenesis of the corpus callosum; non-ambulatory; non-verbal
Care Facility: Harvard Community Health Plan -- Boston, MA
Skills and Interests: Dance
Experience: Public speaking; promoting legislation; dance instruction
Related Employment: M.Ed., former special education teacher

Pauline Sherman
23 Foster Road
Sandwich, MA 02537
508 888-7201

Child's Disabilities: No diagnosis -- non-verbal; developmental delay; hypotonia
Affiliations: Birth to Three Network; People Empowering People (PEP)
Care Facility: Boston Children's Hospital -- Boston, MA
Skills and Interests: Early intervention
Experience: Family leadership training; local Coordinating Council -- past Parent Advisory Committee Chairwoman; starting or maintaining parent/family support groups; public speaking; training parents, health care providers, and teachers; promoting legislation
Languages other than English: Sign language

Sandra Slavet
42 Grove Street
Randolph, MA 02368
617 986-4119

Child's Disabilities: Down syndrome
Affiliations: Massachusetts Down Syndrome Congress; "Parents First Call" Network -- Leader; Step I Early Intervention Program; Parent-Teacher Council -- Chairperson; La Leche League International -- Leader
Care Facility: Boston Floating Hospital (New England Medical Center) -- Boston, MA
Skills and Interests: Early intervention programs
Experience: Public speaking; conducting training sessions for early intervention directors in the health department; promoting legislation; starting or maintaining support groups; the state health department's Early Intervention Advisory Council -- Parent Representative
Related Employment: Interpreter for the deaf
Languages other than English: American sign language

Janet Vohs
*Federation for Children with Special Needs
95 Berkeley Street
Boston, MA 02116

Child's Disabilities: Cerebral palsy
Affiliations: *Federation for Children with Special Needs -- Publications Director
Skills and Interests: Integration; community living; assisted technology
Experience: Public speaking; leading training for health care providers and teachers; promoting legislation; starting or maintaining parent/family support groups; working with state health departments; newsletters
Related Employment: Publications Director, *Federation for Children with Special Needs

MICHIGAN

Kathleen Adams
314 Riley Street
Lansing, MI 48910
517 483-2485
517 484-1955

Child's Disabilities: Down syndrome (08/15/83)
Affiliations: Respite group (trading babysitting within pools of families with children with similiar disabilities); Sparrow Hospital -- Five-year Planning Committee and Architectural Engineering and Decor Facilitator
Care Facility: Sparrow Hospital -- Lansing, MI
Related Employment: Architectural Engineering and Decor Facilitator, Sparrow Hospital

Mark and Ramona Adams
3713 Maybel
Lansing, MI 48911
517 882-2184

Children's Disabilities: One child with Smith-Lemli-Opitz syndrome; kidney failure; Second child with Down syndrome; trisomy 21H; speech impairment
Affiliations: Share (parent support group) -- Advocate
Care Facility: Detroit Children's Hospital and Michigan State University Clinic Center -- Detroit, MI
Skills and Interests: Parent networking locally, statewide, and nationally by location and circumstances; parent training
Experience: Starting and maintaining support groups

Judy Barnes
3555 Fleetwood
Kalamazoo, MI 49008
616 382-1639

Child's Disabilities: Metachromatic leukodystrophy (10/02/74)
Care Facility: Bronson Methodist Hospital -- Kalamazoo, MI
Skills and Interests: Helping brothers and sisters and parents of children with special needs to cope
Experience: State committee on education of the medically fragile child; training teaching nurses
Related Employment: R.N., Home health care

Rebekah Berman
7931 Appoline
Dearborn, MI 48126
313 582-7292

Child's Disabilities: Williams syndrome (including severe congenital heart defects) (03/30/89)
Affiliations: Family Support Group of Family & Neighborhood Services of Wayne County -- Parent consultant and Group leader
Care Facility: University of Michigan Medical Center -- Ann Arbor, MI
Skills and Interests: Respite care; parent resource information
Experience: Local ICC -- Wayne County, MI; compiling resource directory for parents; starting or maintaining parent/family support groups; public speaking; training parents, health care providers, or teachers; promoting legislation
Languages other than English: Spanish

Valerie M. Constance
7225 Warren Road
Ann Arbor, MI 48105
313 662-1563

Child's Disabilities: Down syndrome; Hirschsprung's disease; leukemia; bowel impaction; failure to thrive; required nasogastric intestinal feeding tube and broviac catheter
Affiliations: Alpha Productions, Educational Innovations in Health Care -- Consultant; ACCH -- past President, Michigan Regional Affiliate; National Parent Network on Disabilities; Wise Mothers, Inc.; Ann Arbor Citizens Advisory Committee for Adult Education; National Council of Teachers of English
Care Facility: University of Michigan, Mott Children's Hospital -- Ann Arbor, MI; Detroit Children's Hospital -- Detroit, MI; Beaumont Hospital -- Royal Oak, MI
Skills and Interests: Parent and systems advocacy; parent-to-parent support; rights of individuals with disabilities
Experience: Seeking publisher for my book, *Lindsay, The Story of a Down Syndrome Child and her Family*; public access T.V. appearance on "Healthy Issues," about finding a pediatrician, including interview questions; P.L. 99-457; teaching course in dealing with doctors and parent-physician partnerships; community education of the Ann Arbor Public Schools; fundraising; newsletters; grant writing; public relations; marketing; public speaking; training parents, health care providers, or teachers; starting or maintaining support groups

Yvonne De Paepe
1105 South Clinton Avenue
St. Johns, MI 48879
517 224-4383

Child's Disabilities: No diagnosis (09/16/67)
Affiliations: Clinton County Support Group for Parents of Children with Special Needs -- Founder
Care Facility: University of Michigan Hospital -- Ann Arbor, MI
Skills and Interests: Parent-to-parent support; legislative issues; improved medical and education services; accident prevention; rights of brothers and sisters; fathers' rights; equal human rights
Experience: Promoting legislation; starting or maintaining support groups; working with state health departments and local and state agencies; respite care; public speaking

Silvia Dunne
348 Springreene
Ada, MI 49301
616 676-2706

Children's Disabilities: Brain damage; G-tube; frequent suctioning (01/01/87); Brain damage; tracheostomy; G-tube (12/27/84); Brain injury from child abuse at age four months; cerebral palsy (02/24/86); Children with Trisomy 22; Trisomy 7
Affiliations: Families at Heart (support group for parents of children with heart defects)
Care Facility: Butterworth Hospital -- Grand Rapids, MI

Skills and Interests: Respite services; improving care and understanding in the hospital setting; foster care

Experience: Helping to organize parent support group within the school district; working with staff at Butterworth Hospital to improve communication skills between parents and health care professionals and to improve understanding of children with chronic and terminal illness and their families; starting or maintaining parent/family support groups; public speaking; training parents and health care providers

Related Employment: Licensed Practical Nurse, Pediatrics; Foster parent for children with special needs; Respite provider for health department

Languages other than English: German

Connie Fischer
44 John Ball Park Drive, N.W.
Grand Rapids, MI 49504
616 458-8744

Child's Disabilities: Trisomy 18 (1970-1987)

Affiliations: Mercy Respite Care Corporation -- First President; SKIP of Michigan; Foundation for Hospice and Home Care; Families and Friends of Disabled Persons

Care Facility: Butterworth Hospital -- Grand Rapids, MI

Skills and Interests: Home care and insurance for children with medical fragility; education and awareness of family needs and support in long term, chronic, catastrophic illness in children; advocacy respite services; insurance issues

Experience: Public speaking; promoting legislation; starting or maintaining support groups; working with state health departments

Related Employment: R.N.; Volunteer

L. Bryn Fortune
34746 Bunker Hill Drive
Farmington Hills, MI 48331
313 782-4011
313 553-2776

Child's Disabilities: Metabolic disorder; immune deficiency; carnitene deficiency; failure to thrive; congestive heart failure; neuromuscular disorder; hearing impairment (11/17/84)

Affiliations: Michigan Department of Public Health -- Parent Participation Project; Oakland County Family Support Network -- Co-coordinator; Michigan FSN Steering Committee; Children's Hospital of Michigan -- Neurology Parent Professional Advisory Council, Inc., (NPPAC)

Care Facility: Children's Hospital of Michigan -- Detroit, MI

Skills and Interests: Financing issues; interagency collaboration on state and local levels

Experience: Designing training program for Department of Special Education; Parents in Care Conference -- Co-Coordinator; "Skills Sharing Day" Conferences -- Coordinator; Family-Centered Care Task Force, Children's Hospital of Michigan; state-level interagency workgroups looking at financing issues; Task Force for Michigan Department of Public Health (provider approval guidelines for providers of CSHCS services); Advisory Council, Children's Special Health Care Services -- Vice Chair; starting or maintaining parent/family support groups; public speaking; training parents, heatlh care providers, and teachers; promoting legislation

Related Employment: Trainer/Parent consultant, Family & Neighborhood Services for Wayne County Resource Development Center

Patrick Alan and Karen Sue Gaffner
9005 East Arnold Lake Road
Harrison, MI 48625
517 539-7427

Children's Disabilities: Asthma and severe allergies (09/30/82); Three children with Mannosidosis (inborn error of metabolism); learning and speech impairment (05/13/77, 01/07/79, and 04/20/81)

Affiliations: Children of Special Needs Support Group

Care Facility: MSU Clinical Center -- East Lansing, MI; CMV Hearing Clinic -- Mt. Pleasant, MI; Midland Allergy Clinic -- Midland, MI

Skills and Interests: Respite care; seeking educational services; special camp programs; working with a sign language specialist

Experience: Involved in a remedial summer camp for children with speech and hearing impairments; training teachers; participating in the Michigan Self-Help Clearinghouse

Dianne L. Haas
21809 Clover Lane
Novi, MI 48375
517 335-8895
313 348-9536

Child's Disabilities: Mental retardation; perceptual handicap; growth disorder (endocrinologically based); speech and language impairment (01/27/70)
Affiliations: Jardon School Parent Advisory and Support Group; Michigan and Oakland County ARC; Michigan Nurses Association; American Nurses Association; Council on Psychiatric Mental Health Nursing; Michigan Association for Children and Adults with Learning Disabilities
Care Facility: Children's Hospital of Michigan -- Detroit, MI
Skills and Interests: Public speaking, particularly related to the development of statewide, family-centered, community-based, coordinated care service structures, advocacy, grant writing; state consultant on same subjects; maternal and child HIV infection; families of children in need of supportive home care program services
Experience: Responsible for statewide program implementation of Locally Based Services in Michigan; providing consultation and training workshops to state health department personnel; project oversight of the Pediatric AIDS Demonstration Project, Children's Hospital of Michigan; Michigan Specialized Home Care Program; interagency and multidisciplinary collaboration and coordination; implementation of P.L. 99-457; evaluation research
Related Employment: Ph.D., Nursing; R.N.; Chief Nurse Consultant, Children's Special Health Care Service, Michigan Department of Public Health

Patricia and John Hanley
1154 West Pratt Road
Dewitt, MI 48820
517 669-8658

Children's Disabilities: Twins with cerebral palsy; visual impairments (08/06/79)
Affiliations: United Cerebral Palsy of Lansing; SEPAC (Special Education Parent Advisory Committee); The Parent Support Group
Skills and Interests: Parent-to-parent support; advocacy for families of children with special needs; legislation; issues involving children with physical disabilities and their families
Experience: United Cerebral Palsy of Lansing -- past Treasurer; Center Program School, Lansing School District -- PTA Chairperson; public speaking; promoting legislation; starting or maintaining support groups; working with state health departments
Related Employment: Patricia -- developing and teaching course titled *Barrier Free Design* (covers commercial and residential construction and renovations), Lansing Community College Architectural Studies Center -- Lansing, MI

Beverly McConnell
2990 Syckelmoore
Trenton, MI 48187
313 256-3684

Child's Disabilities: Cerebral palsy; apnea; epilepsy; mental retardation
Affiliations: Northwestern Guidance Clinic Respite Care Program; National Parent Resource Center; ACCH -- National Advisory Committee on Family-Centered Care; ARC-Michigan; Michigan Genetics Advisory Committee; Great Lakes Regional Genetics Group; Children's Hospital of Michigan -- Task Force on Family-Centered Care
Care Facility: Children's Hospital Michigan -- Detroit, MI
Skills and Interests: Development of parent-to-parent networks; impacting public policy to reflect the philosophy of family-centered care
Experience: Public speaking; training parents on P.L. 94-142; support groups; working with state agencies; promoting legislation
Related Employment: Director, Parent Participation Program, Children's Special Health Care Services, MI Department of Public Health

Marcia Radin
3553 Burbank
Ann Arbor, MI 48105
313 769-4638

Child's Disabilities: Neurological impairment (01/13/83)
Affiliations: Family Support Network of Michigan -- Washtenaw County Co-Coordinator and State Steering Committee Member
Care Facility: Private physician
Skills and Interests: Early intervention; problems of neonatal behavioral disorganization/ neurological insults in NICU
Experience: ICC for 99-457; Merrill Palmer

Institute -- Advisory Committee, "Early Intervention Study of Risk Indicators for Developmental Delay -- Indentification and Definition;" starting or maintaining parent/family support groups; public speaking; training parents
Related Employment: Playgroup coordinator for 99-457 Demonstration Grant for Washtenaw County, MI

Deborah Russell
6318 Eagle Ridge
Kalamazoo, MI 49004
616 342-6121
517 487-1755
616 382-2828

Child's Disabilities: Tracheostomy; vocal cord paralysis; gastroesophageal reflux; tracheal stenosis (09/11/82)
Affiliations: State Interagency Coordinating Council for Handicapped Infants and Toddlers; Michigan Coalition for Access to Health Care; former SKIP Chapter Organizer; ARC-Michigan
Care Facility: Children's Hospital of Michigan -- Detroit, MI; Children's Memorial Hospital -- Chicago, IL
Skills and Interests: Health care financing; family support; home care; inclusive programming; skill in systems advocacy; public speaking; promoting legislation; policy analysis; conference planning; writing
Experience: Task forces and advisor to state public health and human service programs; consultant on family-centered programs for children with complex health needs; testimony at state and federal level; parent support and networking
Related Employment: Michigan Coalition for Access to Health Care, Health Access Project, Michigan Protection and Advocacy Service
Languages other than English: French

MINNESOTA

Mark and Jane Henkel
RR 2 Box 56
Clara City, MN 56222
612 847-3586

Child's Disabilities: Incontinentia pigmenti; epilepsy (12/07/84)
Care Facility: Willmar Medical Center -- Willmar, MN

Sharman Davis Jamison
3901 5th Avenue, S.
Minneapolis, MN 55409
612 827-2966
612 824-6518

Child's Disabilities: Autism; profound deafness (12/13/70)
Affiliations: Lanterman Regional Center; National Society for Autism; *PACER Center, Inc.
Care Facility: Private physician
Skills and Interests: Accessibility and delivery of information for underserved and minority populations
Experience: Served on task force related to improvement of health and education; starting or maintaining parent/family support groups; public speaking; training parents, health care providers, or teachers; promoting legislation
Related Employment: Program Coordinator, Supported Employment Technical Assistance Project, *PACER Center, Inc.

LuAnn Jelinek
140 West Richmond Street, S.
St. Paul, MN 55075
612 455-3903

Children's Disabilities: Prematurity (25 weeks gestation); cerebral palsy; hyperactivity; Profound mental retardation; seizure disorder; cleft lip and palate; crying disorder; severe stomach disorder; scoliosis; medical fragility
Affiliations: MNASH; ARC/Suburban; Project Dakota Outreach -- Parent consultant
Skills and Interests: Spiritual needs of children with disabilities; integration; parent-to-parent support network; parent advocacy
Experience: Public speaking; leading training for health care providers and teachers; promoting legislation; starting or maintaining support groups; working with state health departments; seminars on integration and home visiting for parents and professionals
Related Employment: Social worker

Diana L. Johnson
10 County Highway, #4
Wrenshall, MN 55797

Child's Disabilities: Congenital adrenal hyperplasia (CAH) (01/24/87)

Affiliations: CAHSA (Congenital Adrenal Hyperplasia Support Association) -- Founder and President
Care Facility: University Hospitals and Clinics -- Minneapolis, MN
Skills and Interests: Early intervention; parent and professional education
Experience: Working on manual about CAH; starting or maintaining parent/family support groups; public speaking
Languages other than English: Swedish

Shirley A. Kramer
13512 Parkwood Lane
Burnsville, MN 55337
612 892-5548

Children's Disabilities: Premature twins -- One with myelomeningocele; hydrocephalus; congenital spinal kyphosis; The other with cerebral palsy; hydrocephalus; seizure disorder resulting from intraventricular hemorrhages
Affiliations: Minnesota's State Coordinating Council for P.L. 99-457; ACCH; ARC; Minnesota Association for Persons with Severe Handicaps (MNASH); Spina Bifida Association of Minnesota (SBAM); Federal Interagency Coordinating Council -- Parent Representative; Parent/Patient Advisory Committee, Minneapolis Children's Health Center -- Chairwoman
Care Facility: Minneapolis Children's Health Center -- Minneapolis, MN
Skills and Interests: Seeking to provide more comprehensive and better coordinated interventions involving education, health, and social services, particularly in home care
Experience: Public speaking; conducting training sessions for health care providers/teachers; lobbying state legislature for Mental Retardation waiver; worked with state health department on task force to develop health care standards for persons with developmental disabilities; participated in the Partners in Policy-Making Grant of the Governor's Planning Council on Developmental Disabilities to train individuals to be leaders in disability policymaking; working with local United Way; developed workshops on home care for ARC; developed personal computerized home care management system for medical, developmental, and rehabilitative needs of twins with disabilities

Arnold L. and Joyce E. Lindgren
5505 South 14th Avenue
Minneapolis, MN 55417

Children's Disabilities: Total blindness (04/06/72, adopted); Legal blindness; post-polio sequelae; scoliosis (03/10/72, adopted); Legal blindness; learning disabilities; congenital nerve hearing loss (08/20/73, adopted); Adult-onset rheumatoid arthritis; epilepsy (10/17/66, adopted); Learning disability (12/03/68, adopted); Medical fragility, including babies with cocaine exposure (foster infants); Total-Colon Hirschsprung's disease (12/14/89, grandson)
Affiliations: *PACER Center, Inc.
Care Facility: University Minnesota Clinics and Minneapolis Children's Hospital -- Minneapolis, MN
Skills and Interests: Concern that families and children who are culturally diverse have appropriate services and that parents are treated as partners
Experience: Served on the Minnesota Maternal and Child Health Task Force; served on advisory task force for the Minneapolis Department of Health High Risk Tracking System for P.L. 99-457; National Network of Parent Centers, *PACER Center, Inc -- former National Childhood Technical Assistance Resource Specialist; starting or maintaining parent/family support groups; public speaking; training parents; promoting legislation
Related Employment: Foster parent of infants with medical fragility; Consultant on family issues related to children with special needs; Writer

Marijo McBride
911 Hall Avenue
West St. Paul, MN 55118
612 624-4848
612 457-8138

Child's Disabilities: Attention deficit disorder (03/11/76)
Affiliations: Metropolitan Center for Independent Living; TASH; MNASH; Senior Agenda for Independent Living; Minnesota Early Childhood Inclusion Work Group
Care Facility: Group Health -- St. Paul, MN
Experience: Developing and implementing pilot project; public speaking; conducting training sessions for health care providers, teachers, parents, and consumers; promoting legislation;

starting or maintaining support groups
Related Employment: Qualified Mental Retardation Professional; Social Worker; Parent Case Management Coordinator, University of Minnesota Institute on Community Integration -- Minneapolis, MN

Virginia Richardson
4044 Oakland Avenue, S.
Minneapolis, MN 55407
612 827-2966
612 822-3464

Child's Disabilities: Mental retardation; epilepsy
Affiliations: *PACER Cener, Inc. -- Parent Training Coordinator
Skills and Interests: Parent training in P.L. 94-142
Related Employment: Parent Training Coordinator, *PACER Center, Inc.

Linda Rother
782 Sunset Drive
Eagan, MN 55123
612 454-3537

Children's Disabilities: Learning disability; fluctuating hearing acuity (08/30/76); Mental retardation; seizures; chronic migraine headaches; chronic urinary tract infection (12/12/79); Mental retardation; infantile apnea; seizures; ataxia; hyperflexia; hypotonia (03/01/83)
Affiliations: ARC -- Board Member; Minnesota Association for Persons with Severe Handicaps (MNASH); Minnesota Association for Children with Learning Disabilities (MACLD)
Care Facility: St. John's Hospital and St. Paul Children's Hospital -- St. Paul, MN
Skills and Interests: Community integration and normalization; mainstreaming in education; parent/professional collaboration; communication with policymakers and education and county/state officials; computer usage for education; technology
Experience: Metro Advisory Council on Developmental Disabilities; County Interagency Early Intervention Committee -- past Member; public speaking; leading training for health care providers/teachers; promoting legislation; working with state health departments; Minnesota Governor's Planning Council on Developmental Disabilities; Legal Advocacy Advisory Committee; The Center for Children/Youth with Chronic Illness and Disabilities -- Advisory Committee; Metro Council Advisory Committee on Developmental Disabilities -- past Chair; trained in personal futures planning and frameworks for accomplishment; Partners in Policymaking; certified trainer in positioning, positive learning techniques technology and individual plans
Related Employment: Emergency Room R.N.; M.A., Public Administration

Celia Shapland
4322 Rustic Place
Shoreview, MN 55126
612 827-2966
612 482-1811

Child's Disabilities: Cerebral palsy; mental retardation (11/16/74)
Affiliations: ARC; *PACER Center, Inc.
Care Facility: North Suburban Family Physicians -- Shoreview, MN
Skills and Interests: The health care system and financing health care; planning two workshops for parents about these subjects
Experience: Served on parent advisory board for early intervention; working with state health department to develop resource directory; public speaking; training parents and health care providers
Related Employment: Regional Coordinator, CAPP; Staff member, Supported Employment Parent Training Technical Assistance Project, *PACER Center, Inc.

Barbara Staub
20233 Quinnell Avenue, N.
Scandia, MN 55073
612 433-3284

Child's Disabilities: Miller-Dieker syndrome (lissencephaly) (12/16/86)
Affiliations: *PACER Center, Inc. -- CAPP Project
Care Facility: Fairview-Riverside -- Minneapolis, MN
Experience: Public speaking; training health care providers
Related Employment: Pediatrician -- White Bear Lake, MN

Ronald and Judy Vessey
4610 Wooddale Avenue
Edina, MN 55424
612 925-2596

Child's Disabilities: Klippel-Trenaunay-Weber (K-T) syndrome (03/25/81)
Affiliations: Klippel Trenaunay Support Group -- Chairperson; NORD
Care Facility: Mayo Clinic -- Rochester, MN
Experience: Starting or maintaining support groups
Related Employment: Judy -- Social Worker; Ronald -- Physician

MISSISSIPPI

Stan and Debbie McCaffrey
12458 North Oaklawn Lane
Biloxi, MS 39532
601 832-0885
601 392-0668

Child's Disabilities: Werdnig-Hoffmann disease; ventilator dependent; G-Tube
Affiliations: Families of S.M.A. (Spinal Muscular Atrophy); Muscular Dystrophy Association; SKIP of Mississippi -- Director and Coordinator of summer camps for South Mississippi, Louisiana, and Alabama; Handicapped Children of Harrison County -- Parent Advisor and Director of pilot program for delivery of PT, OT, ST, and RT to children county-wide who are not covered by other programs
Care Facility: Memorial Hospital -- Gulfport, MS; Children's Hospital -- New Orleans, LA
Skills and Interests: Advocacy for families to receive maximum services
Experience: Public speaking; fundraising

Shirley Jones Miller
456 Stillwood Drive
Jackson, MS 39206
601 939-8640, ext. 140
601 362-7128

Child's Disabilities: Language delay; behavior problems (07/82)
Affiliations: Encourage Family Support Group; Jackson Public Schools Parents' Group -- Acting President; Mississippi Parent Advocacy Center; Mississippi Families as Allies -- President; Mississippi State Mental Health Planning Council; Federation of Families for Children's Mental Health -- State contact; CASSP -- Statewide and Region II Task Forces; Mental Health Case Review Team; Human Resource Advisory Committee; Mississippi Early Services for the Handicapped -- Treasurer; Jackson Public School Five-Year Planning Committee; Early Intervention Program -- Parent Trainer/Consultant
Care Facility: Children's Medical Group -- Jackson, MS
Skills and Interests: Early intervention; developing communication skills with parents; transition
Experience: Serving as member of the Hudspeth Center Advisory Committee; parent/professional collaboration trainer; public school behavioral consultant; Head Start consultant; starting or maintaining parent/family support groups; public speaking; promoting legislation
Related Employment: Consultant, Parent Advocacy Center

Kathy Odle
425 Louisa Street
Pearl, MS 38859
601 354-0341
601 354-8845

Children's Disabilities: Two children with Neuroaxonal dystrophy (10/04/74 and 06/15/77)
Affiliations: North Mississippi Coalition for Handicapped Residents -- Director; Children's Medical Program (CMP); Parent Advisory Committee -- Chairperson; ACRES; Mississippi's Association of School Attendance Counselors -- Executive Committee; Mississippi Parent Network -- Coordinator
Care Facility: University of Mississippi Children's Hospital and Blake Clinic for Children, and Children's Rehabilitational Center -- Jackson, MS
Skills and Interests: Parent-to-parent support; rural respite and home care services; increased financing for community-based services; early intervention; legislative advocacy
Experience: Children's Medical Program Advisory Board Member; North Mississippi Coalition for Handicapped Residents -- Newsletter editor; Interagency Coordinating Council; CMP Parent Consultant for staff training on family-centered care; CAASP Task Force

Member; public speaking; leading training for health care providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments
Related Employment: Children's Medical Program Parent Consultant, Mississippi Health Department

Anne Presley
332 New Market Drive
Jackson, MS 39202
601 922-3210
601 373-0948

Child's Disabilities: Hydrocephalus (09/01/73)
Affiliations: *Association of Developmental Organizations of Mississippi (ADOM) -- Executive Director; Mississippi Parent Advocacy Center (MS-PAC) -- Director; Mississippi Autistic Society -- Board Member; Coalition for Citizens with Disabilities -- Board Member; ACCH
Care Facility: Children's Medical Group, Neurosurgery Clinic, Mississippi Baptist Medical Center -- Jackson, MS
Skills and Interests: Parent advocacy; networking in rural areas; minority involvement; parent training; legislative updates; funding; parent/professional partnerships; parent support group development/training; respite care; community-based services; SSI and Medicaid; P.L. 99-142; public speaking
Experience: Governor's Interagency Coordinating Council; National Network of Parents on Disabilities; South Regional TAPP Site for Technical Assistance for Parents in Mississippi; training on P.L. 99-457; information packets on pre-school services; training module on health care/family-centered care; training on brothers and sisters and parenting children with disabilities; starting or maintaining parent/family support groups; public speaking; training parents, health care providers, and teachers; promoting legislation
Related Employment: Executive Director, ADOM/MS-PAC

Kathy Tullos
510 Woodland Hills Drive
Philadelphia, MS 39350
601 656-6855

Child's disability: Ketotic hypoglycemia (08/13/81)
Affiliations: Advocates for the Exceptional -- Founder and Director; ARC -- State Vice President; Coalition for Citizens with Disabilities -- Board of Directors
Care Facility: Riley Memorial Hospital -- Meridian, MS
Skills and Interests: Education (Home Bound Programs provided by the School District); teaching parent advocacy; supported employment; respite care; affordable major-medical insurance
Experience: Starting parent groups; conducting workshops; advocating for rights for people with all types of disabilities; conducting needs assessments; providing care coordination; information services and resources; parent-to-parent support
Related Employment: Director, Advocates for the Exceptional; Parent advisor, Infant Toddler Program, State Department of Health

MISSOURI

Bill and Valeri Lane
1514 St. Christopher
Columbia, MO 65203
314 874-0652

Child's Disabilities: Arnold-Chiari syndrome; myelomeningocele; NG feedings; ventilator dependence; oxygen dependence (02/06/85)
Affiliations: Arnold-Chiari Family Network
Care Facility: University of Missouri and Columbia Hospital and Clinics -- Columbia, MO
Skills and Interests: Public speaking; parent advocacy; legislative advocacy; integration/inclusion; adequate respite care; promoting local interagency coordination; augmentative communication (Touch Talker)
Experience: Public speaking; conducting training at the state level for health care providers/teachers; promoting legislation; working with local parent support group; Missouri State Interagency Coordinating Council of P.L. 99-457 -- Parent Representative; Bureau of Special Health Care Needs -- Parent Representative and Advisory Committee; working with hospital to coordinate seminar on family-centered care, to include parents of chronic care children in residency training, and to start parent resource library; Bill -- Boone County ARC -- Executive Secretary
Related Employment: Teacher, Hickman High School -- Columbia, MO
Languages other than English: Sign language

Mary McFarland
Route 1 Box 306
Salem, MO 65560
314 729-5030

Child's Disabilities: Down syndrome (09/30/87)
Affiliations: Rolla Down Syndrome Support Group; Region VII Parent Support Group -- Secretary/Treasurer; *Missouri Parents Act (MPACT) -- Board Member; Show Me Choices (Missouri's Parent/Consumer Advocacy Coalition) -- Charter Member and Parent Trainer for Region VII; S.B. 40 Chairperson; Region VII Parent's Advisory Council (PAC)
Care Facility: Cardinal Glennon Memorial Hospital for Children -- St. Louis, MO
Skills and Interests: Early intervention; parent-to-parent support and correspondence; P.L. 94-142; mainstreaming; parent/professional collaboration and communication; local parent partnerships in accessing resources and supports; materials on Down syndrome; education, advocacy, and rights of person with developmental disabilities; promoting access to Lekotek or toy lending libraries in rural areas; legislative lobbying for passage in Missouri of P.L. 99-457 and the Americans with Disabilities ACT; usefulness of PC's in enhancing learning skills acquisition for preschoolers with developmental disabilities (ages zero to eight)
Experience: Writing; promoting legislation to disallow non-qualified therapies for school-aged children with disabilities; development of Lekotek's Compu-play Center and/or Joymobile for children in rural areas with developmental disabilities; DESE's First Steps II Conference Planning Committee Member

Lynna Rice
2402 Highland Drive
Columbia, MO
314 446-1457

Child's Disabilities: No diagnosis (08/26/86)
Affiliations: Parents Reaching Out -- Founder
Care Facility: University of Missouri Hospital and Clinics -- Columbia, MO
Skills and Interests: Early intervention; educational issues
Experience: M-TIKES Advisory Panel; Missouri Department of Education -- 94-142 Advisory Panel; starting or maintaining parent/family support groups, public speaking; training parents and health care providers; promoting legislation

Dana Vouga
1611 Clayton Spur Court
Ellisville, MO 63011
314 227-4411

Child's Disabilities: Williams syndrome (05/29/84)
Affiliations: Williams Syndrome Association -- National Chairman
Care Facility: St. Louis Children's Hospital -- St. Louis, MO
Experience: Starting or maintaining parent/family support groups; public speaking; training parents, health care providers, and teachers

MONTANA

Katharin A. Kelker
2210 Fairview Place
Billings, MT 59102
406 657-2055
406 252-7596

Children's Disabilities: One child with cleft palate; birth defects affecting eyes and internal organs; Second child with mental retardation
Affiliations: *Parents, Let's Unite for Kids (PLUK) -- Project Director
Care Facility: Billings Clinic -- Billings, MT
Skills and Interests: Advocacy; editing a newsletter
Experience: Public speaking; conducting training sessions for health care providers/teachers; promoting legislation; starting or maintaining parent/family support groups; working with state health department as an advisor for programs and grants
Related Employment: Teacher; Project Director, *PLUK

NEBRASKA

Brenda and David Blizzard
1013 Creighton Road
Papillion, NE 68128-6251
402 339-0703

Child's Disabilities: Survived Sudden Infant Death Syndrome; severely brain damaged (10/01/84)
Care Facility: Children's Hospital; University of

Nebraska Medical Center
Skills and Interests: Respite programs; parent training programs to relieve anxieties related to health care for individuals with disabilities
Experience: Public speaking; training health care providers

Anne M. Lauritzen
643 Eastridge Drive
Lincoln, NE 68510-3919
402 488-5859

Child's Disabilities: Spina bifida; hydrocephalus; hearing impairment; visual impairment
Affiliations: Spina Bifida Association of Star City (Lincoln) -- President, Board of Directors; Spina Bifida Association of America (SBAA); Pilot Parents of Lincoln; Region V Developmental Disabilities Council; *Nebraska Parents' Information and Training Center -- President, Advisory Board; State Respite Care Advisory Board Member; Comprehensive Health Insurance Pool (CHIP) -- Nebraska Policyholders Association Board Member
Care Facility: St. Elizabeth Community Health Center -- Lincoln, NE; University of Michigan Medical Center -- Ann Arbor, MI
Skills and Interests: Information and referral; education advocacy; parent-to-parent networking; conference planning; in training to be a paralegal with an emphasis on disability rights
Experience: Public speaking; lobbying for legislative change; working with Department of Social Services revising the plan for medical services of Nebraska for children with special health care needs; SBAA -- Conference Planning Committee and Representative to OSERS' Family Leadership Conference; participation on committee to develop legislation to enact the developmental disabilities definition in Nebraska to promote equal services for all disabilities; OSERS and NIDRR grant review teams

B.J. and Chris Reed
113 South 50th Avenue
Omaha, NE 68132
402 554-2625
402 556-5509

Child's Disabilities: Short bowel syndrome (09/10/85)
Care Facility: Children's Memorial Hospital and Swanson Center for Nutrition -- Omaha, NE
Skills and Interests: Parent-to-parent support; insurance issues for families with children with chronic illness
Experience: Public speaking; promoting legislation; starting or maintaining support groups; working with state health departments
Related Employment: Professors of Public Administration

NEVADA

Deborah Davis
3015 Heights Drive
Reno, NV 89503
702 747-0669

Child's Disabilities: Two children with congenital fibertype disproportion
Affiliations: CHANCE (Coalition for Handicapped Children's Education) -- Executive Director; N-STEP (Nevada Specially Trained Effective Parents) -- Information Coordinator
Care Facility: St. Mary's Hospital -- Reno, NV
Skills and Interests: Support for families; training on P.L. 94-142; helping families learn coping skills; parent/professional collaboration; information and referral for families
Experience: Nevada Interagency Coordinating Council; Standards Revision Task Force; Very Special Arts -- Board Member; HAPPY (Home Activity Program for Parents and Youth) -- Advisory Board Member; Special Children's Clinic -- Parent Auxiliary and Board Member; public speaking; leading training for health care providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments
Related Employment: Executive Director, CHANCE; Information coordinator, N-STEP

Diana J. Dowling
2621 Cathedral Lane
Las Vegas, NV 89108
702 799-7401
702 658-9022

Child's Disabilities: HIV+ (ARC) (01/01/88)
Affiliations: REACH OUT (Relieving Every AIDS Child's Hurt, Our Ultimate Task) --

Secretary; AFAN (Aide for AIDS of Nevada) -- Significant Others (counseling group)
Child's Disabilities: University Medical Center -- Las Vegas, NV; NIH -- Bethesda, MD
Skills and Interests: Respite; education of HIV+ children and adults
Experience: Starting or maintaining parent/family support groups; public speaking; training parents, health care providers, and teachers; promoting legislation
Related Employment: Principal, John F. Miller School for Special Education -- Las Vegas, NV

Eric and Carolyn Craig Ingbar
2420 Woodcrest Lane
Carson City, NV 89701
702 885-2864

Child's Disabilities: Down syndrome (06/26/86)
Affiliations: Mile High Down Syndrome Association; National Down Syndrome Congress
Care Facility: Private physician
Skills and Interests: Better quality services; parent support groups; parent information
Experience: Served on the state Interagency Coordinating Council for P.L. 99-457

Karen Taycher
4112 Fortune Drive
Las Vegas, NV 89107
702 870-7050
702 878-4618

Child's Disabilities: Visual impairment; high frequency hearing loss; seizure disorder; ataxic cerebral palsy (01/11/84)
Affiliations: Coalition for Handicapped Children's Education -- State Chairperson; Friends of the Visually Impaired; Clark County School Board -- Special Education Ad Hoc
Care Facility: South West Medical Center and Humana Hospital Sunrise -- Las Vegas, NV; UCLA Medical Center -- Westwood, CA
Skills and Interests: Advocacy for full range of needs for families of children with disabilities birth to 21
Experience: ICC-- Substitute Member and Subcommittee; Nevada Developmental Disabilities Committee; Nevada Very Special Arts; starting or maintaining parent/family support groups; public speaking; training parents and teachers; promoting legislation
Related Employment: Family Services Coordinator, Nevada Association for the Handicapped

David and Shannon Ward
3105 West Plumb Lane
Reno, NV 89509
702 323-6404

Child's Disabilities: Omphalocele (corrected); severe retardation; seizure disorder; hearing loss; very poor vision
Affiliations: Parent Support Group, Marvin Picollo School
Care Facility: Moffitt Hospital/University of California -- San Francisco, CA
Skills and Interests: Impact of environment on health care; networking with other parents of children with omphaloceles; adoption of children with special needs
Experience: Public speaking; conducting training sessions for health care providers/teachers
Related Employment: Master teacher, Child and Family Center (preschool programs), University of Nevada at Reno

NEW HAMPSHIRE

John A. and Pamela K. Allen
Allen Mine Road
P.O. Box 424
Alstead, NH 03602

Child's disabilities: Phenylketonuria (PKU) (12/31/86)
Care Facility: Boston Floating Hospital, New England Medical Center -- Boston, MA

Bonnie and Skip Dunham
15 Silver Doe Lane
Merrimack, NH 03054
603 224-7005 (Bonnie)
603 424-4024

Child's Disabilities: Down syndrome
Affiliations: Northern New England Down Syndrome Congress; Pilot Parents of Nashua Area; New Hampshire ARC
Care Facility: Hitchcock Clinic -- Nashua, NH

Skills and Interests: Integration in school and community settings; transition from school to work
Experience: Starting or maintaining parent/family support groups; public speaking; training parents; promoting legislation
Related Employment: Parent trainer, *Parent Information Center

Martha-Jean and Robert Madison
RFD #1 Box 3107
Pittsfield, NH 03263
603 942-5540

Children's Disabilities: Splenectomy (1977); Mild hearing impairment (1978); Multiple handicaps (1982); Emotional delay (1983); Severe cerebral agenesis (1985 to 1987); Prematurity (1985); Prematurity; multiple handicaps; technology dependence (1985); Down syndrome; repaired heart defect; hyperthyroidism (1987); Down syndrome (1989)
Affiliations: Bureau of Special Medical Services, New Hampshire Health Department -- Advisory Council; New England SERVE -- Executive Board; New Hampshire Special Families United -- President; *Parent Information Center; New Hampshire Foster Parent Association -- Board Member; Town Budget Committee Chair; Good Shepard School -- Board Member; New Hampshire Association of Retarded Citizens; New Hampshire Department of Developmental Services
Care Facility: Concord Clinic -- Concord, NH; Mary Hitchcock Hospital -- Hanover, NH
Skills and Interests: Workshops on disability awareness; parent-to-parent support; legislative lobbying; inclusion for people with disabilities in educational setting and community; specialized foster care; adoption of children with disabilities
Experience: Public speaking; starting or maintaining support groups; conference planning; training workshops for parents and professionals
Related Employment: Respite coordinator, Area Agency, Specialized Foster Parents for New Hampshire

Terry Ohlson
RFD # 1 Box 773
Warner, NH 03278
603 224-0402

Child's Disabilities: Cerebral palsy (05/13/80)
Affiliations: *Parent Information Center; Early Intervention Network -- Board Member; Area Agency -- Board Member; Pre-school Task Force
Care Facility: Concord Clinic and Neuromotor Clinic -- Concord, NH
Skills and Interests: Augmentative communication; least restrictive education; health care financing
Experience: Serving on the Family Support Task Force and the PreSchool Task Force; public speaking; training parents and teachers; promoting legislation; working with Bureau of Special Medical Services; New England SERVE -- Financing Health Care Committee; parent/professional collaboration
Related Employment: Resource specialist, CAPP and NEC*TAS, *Parent Information Center

NEW JERSEY

Diana Cuthbertson
630 Fairmont Avenue
Westfield, NJ 07090
201 654-4333

Child's Disabilities: Blindness; communication and learning disabilities; recovered from cancer
Affiliations: *Statewide Parent Advocacy Network, Inc. (SPAN) -- Executive Director; Department of Pediatrics and Center for Developmental Disabilities (NJ/UAP), University of Medicine and Dentistry of New Jersey -- Collaborator on family-centered Medical Student Education Project
Care Facility: Children's Hospital of Philadelphia -- Philadelphia, PA
Skills and Interests: Developing training and information materials for parents; family-centered care; collaborative relationships in health and education settings
Experience: Currently involved with Coalition for Inclusive Education; parent training in basic rights under P.L. 94-142 and related legislation; collaborating with professionals in development of information services around early intervention services for learners with blindness and visual impairments and creating options for education in New Jersey
Related Employment: R.N.

Joe and Marirene Heisler
1 Brooks Road
Toms River, NJ 08753
908 244-7635

Children's Disabilities: Von-Hippel Lindau Syndrome (12/28/80 and 01/01/86)
Affiliations: VHL Foundation -- Marirene -- Founder and Executive Director
Care Facility: Wills Eye Hospital -- Philadelphia, PA; Community Medical Center -- Toms River, NJ; (follow-up) NIH -- Bethesda, MD
Experience: Public speaking
Languages other than English: Spanish

Peter and Eileen Losi
4353 Falcon Courts North
McGuire A.F.B., NJ 08641
609 724-0959

Child's Disabilities: Systemic lupus erythematosis (08/22/80)
Affiliations: Parent support group of children with rheumatic disease
Care Facility: Children's Seashore House -- Philadelphia, PA
Skills and Interests: Lupus research (especially hormone relationship)
Experience: Parent Advisory Council for Children with Rheumatic Diseases; public speaking; training parents, health care providers, and teachers
Related Employment: Eileen -- R.N., North Hanover School District

Anne Martin
10 Lockwood Lane
Closter, NJ 07624
201 767-0264

Child's Disabilities: Williams syndrome (10/02/76)
Affiliations: Williams Syndrome Association -- Regional Treasurer; Special P.T.O.; Teaneck Parent Information Center; Involve New Jersey, Inc.; Self-Help Clearinghouse
Care Facility: Private physician
Experience: Serving on the Special P.T.O. Fundraising Committee; Special Olympics Volunteer Chaperon
Related Employment: Teacher's aide

Andrea Portente
19 Haven Avenue
Totowa, NJ 07512
201 942-7554

Child's Disabilities: Ventilator dependence; paralysis from the neck down (06/20/77)
Affiliations: SKIP of New Jersey; National Temps Nursing Agency -- Director and Owner
Experience: Teaching a course to R.N.'s, L.P.N.'s, and families at Morris County College; starting or maintaining parent/family support groups; public speaking; training parents, health care providers, or teachers; promoting legislation

Audrey F. Thomas
RSDSA
P.O. Box 821
Haddonfield, NJ 08033
609 428-6510
215 955-5444

Child's Disabilities: Reflex sympathetic dystrophy syndrome (RSDS)
Affiliations: RSDS Association -- Co-founder and President; Coalition National Organization for Rare Disorders -- Board of Directors; American Pain Society; Coalition for Support of Research at National Institute of Arthritis, Muscular, Skeletal, and Skin Diseases; International Association for the Study of Pain; Coalition of National Alliance for Oral Health -- Founding Member
Care Facility: Thomas Jefferson University Hospital -- Philadelphia, PA
Skills and Interests: Public education about RSDS and use of media; physician referral and counseling of clients and families; applying for research monies
Experience: Public speaking; conducting training sessions for health care providers/teachers; starting or maintaining support groups; articles published in several journals on RSDS; setting up the first RSDS Chapter in the U.S. and helping to develop national data bank on RSDS via a patient questionnaire; working with Jefferson Hospital as volunteer patient and family counselor; presenting papers and poster sessions at several National Pain Management Seminars
Related Employment: R.N.

Jeffrey and Sally Toughill
609 New York Road
Glassboro, NJ 08028
609 881-4911

Child's Disabilities: Histiocytosis/Langerhans cell histiocytosis
Affiliations: Histiocytosis Association of America, Inc. -- Jeffrey -- President
Care Facility: Children's Hospital of Philadelphia -- Philadelphia, PA
Skills and Interests: Newsletters; family support; research
Experience: Public speaking; starting or maintaining support groups for rare disorders; living with a rare disorder

NEW MEXICO

John and Polly Arango
P.O. Box 338
Algodones, NM 87001
505 867-3159
505 867-3660

Child's Disabilities: Cerebral palsy; seizure disorder (06/01/76)
Affiliations: *New Mexico Parents Reaching Out (PRO) -- Polly -- Co-founder and Board Member, John -- Computer and Organizing Consultant; Early Childhood Coalition -- Polly -- Co-Founder; Carrie Tingley Children's Hospital -- John -- Board Member, Polly -- former Board Member; Polly -- Legislative Committee on Children, Youth, and Families; National Resource Parent (CAPP); ACCH Board Member; John -- Legislative Committee on Family-Centered Services; ACCH National Center for Family-Centered Care -- Advisory Board Member
Care Facility: El Pueblo Health Clinic -- Bernalillo, NM; Carrie Tingley Children's Hospital -- Albuquerque, NM
Skills and Interests: Organizing, speaking, and writing skills; transition; family-centered care in health and education settings; organizing advocacy efforts, legislative and otherwise; local, state, and national policymaking for children with special needs and their families; school and community integration; respite services; financial support for parent groups; the foster care system; financing
Experience: Planning statewide conferences; legislative efforts; group decision-making; volunteers in health and education fields; Polly -- ACCH 1988 Leadership Forum Participant; helped to develop legislation for Medically Fragile Children's Program, lowering the school age, and creating high risk insurance pool; El Pueblo Health Clinic -- Board Member; state early childhood conference planning committee; public speaking; sitting on policy committees; writing media pieces; training parents, health care providers, and teachers; PRO newsletter editor; extensive training and organizing experience
Related Employment: Consultant to non-profit agencies and parent organizations; John -- American Bar Association, Legal Services, and AARP; Polly -- freelance writer
Languages other than English: Spanish

Ray and Loretta A. Armenta
6405 Concordia, N.E.
Albuquerque, NM 87109
505 881-1111
505 766-2745
505 821-4763

Child's Disabilities: Sturge-Weber syndrome; Klippel-Trenaunay-Weber (K-T) syndrome (05/16/70)
Affiliations: *Parents Reaching Out (PRO)
Care Facility: Lovelace Clinic -- Albuquerque, NM
Skills and Interests: State support for home care for medically fragile children; medical services for families from diverse racial, ethnic, cultural, and socioeconomic backgrounds; adolescent issues
Experience: Medically Fragile Children's Program Advisory Board Member; public speaking; leading training for health care providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments
Languages other than English: Spanish

Debra Garcia
2108 Violet, S.W.
Albuquerque, NM 87105
505 842-9045
505 877-2404

Child's Disabilities: Down syndrome; congenital heart defect (11/13/84)

Affiliations: Children's Medical Services Advisory Committee -- Secretary; Parent-to-Parent Network; Parents of Preterm Infant Network -- Assignment Coordinator; *Parents Reaching Out
Care Facility: University of New Mexico Hospital and Pediatric Cardiology Associates -- Albuquerque, NM
Experience: Helping to produce pamphlet for project TIEE (Transition & Integration in Early Education), Alta Mira Specialized Family Services; parent and professional training on educational rights for special education children and adults; Regional Advisory Council; starting or maintaining parent/family support groups; public speaking; training parents, health care providers, and teachers; promoting legislation
Related Employment: Assignments Coordinator, Parent-to-Parent Network and Parents of Preterm Infant Network and Trainer, Project Adobe, *Parents Reaching Out

Sue Dailey
P.O. Box 1353
Paguate, NM 87040
505 552-6433

Child's Disabilities: Cornelia de Lange syndrome (03/06/75)
Affiliations: *EPICS Project -- Volunteer
Care Facility: Carrie Tingley Hospital -- Albuquerque, NM; Acima Conocito Laguna (ACL) Hospital -- San Fidel, NM
Skills and Interests: Rural issues
Experience: Training parents, health care providers, or teachers

Catherine Gaines
1547 Luisa Street
Santa Fe, NM 87501
505 983-5156

Child's Disabilities: Severe mental retardation; mild autism; cerebral palsy; metabolic and digestive problems (08/03/81)
Affiliations: *Parents Reaching Out (PRO); Santa Fe ARC -- Board Member; International Society for Alternative and Augmentative Communication; Council for Exceptional Children (CEC); American Speech and Hearing Association (ASHA); Autism Society of America
Care Facility: Arroyo Chamisa Health Center, St. Vincent's Hospital -- Santa Fe, NM
Skills and Interests: Early intervention; augmentative communication; autism; nutritional and allergy problems; advocacy with schools and legislatures; peer support
Experience: State Interagency Coordinating Council for 99-457; Santa Fe public schools 94-142 Planning Committee; State Task Force on Autism and Dually Diagnosed; participating in the state's Ancillary Services Committee Project to train school physicians; starting or maintaining parent/family support groups; public speaking; training parents, health care providers, or teachers; promoting legislation
Related Employment: Speech-Language Pathologist, Early Intervention Program, Las Cumbres Learning Services -- Espanola, NM

Deborah Garcia
2108 Violet, S.W.
Albuquerque, NM 87105
505 842-9045
505 877-2404

Child's Disabilities: Down syndrome; congenital heart disease (11/13/84)
Affiliations: Children's Medical Services Advisory Committee -- Secretary; Parent Support Network -- Assignments Coordinator; Alta Mira Specialized Family Services; *Parents Reaching Out (PRO) -- Board Member
Care Facility: University of New Mexico Hospital and Pediatric Cardiology Associates -- Albuquerque, NM
Skills and Interests: Parent support networking within the hospital system
Experience: Working with the University Hospital and the health department to promote parent support networks; public speaking; training parents, teachers, and health care providers; promoting legislation
Related Employment: Parent Corps Secretary, *PRO

Doris Husted
2533 Cardenas, N.E.
Albuquerque, NM 87110
505 842-9045
505 884-3417

Children's Disabilities: Down syndrome (02/20/81); Asthma (08/29/79)
Affiliations: *Parents Reaching Out (PRO);

Parents Are Capable Case Managers Project -- Project Director; Family Support Project -- Parent Advocate/Trainer
Care Facility: Private physician
Skills and Interests: Early intervention; parents as case managers; services to families in the NICU
Experience: Working with the Children's Medical Services of the state health department, training caseworkers to promote case management by parents; Child Study Team (an interagency team from Lovelace Hospital); supervising parent liaison project in the NICU at the University of New Mexico Hospital; starting or maintaining parent/family support groups; public speaking; training parents, health care providers, and teachers; promoting legislation

Patti Jennings
1107 North Kentucky
Roswell, NM 88201

Child's Disabilities: Down syndrome
Affiliations: *Parents Reaching Out (PRO) -- Board Member; ARC of New Mexico -- Governmental Affairs Director
Skills and Interests: Impacting systems to better serve the needs of persons with disabilities
Experience: New Mexico Legislative Education Study Committee -- Co-chair and Parent Advisor; Handicapped Children's Early Education Plan -- Parent Advisor; Governor's Committee for Chronically Impaired -- Parent Representative; Committee on Uninsurables -- Chairperson; EHA-B Panel Member; lobbyist; drafted and lobbied New Mexico high-risk health insurance pool; Carrie Tingley Children's Hospital -- Board Member; New Mexico Comprehensive Health Insurance Pool -- Chairwoman
Related Employment: Governmental Affairs Director, ARC of New Mexico

Martha J. Johnson
1860 Don Pasqual Road
Los Lunas, NM 87031
505 867-3396
505 865-4395

Children's Disabilities: Attention deficit disorder; hyperactivity (01/04/79); Attention deficit disorder (03/05/71)
Affiliations: *EPICS Project -- Parent Trainer/Advocate
Care Facility: Lovelace Medical Center -- Albuquerque, NM
Skills and Interests: Early identification; early intervention; cultural sensitivity
Experience: AOTA Family-Centered Care Workshop -- Parent Discussant; Minority Panel Session, DEC 1990 Conference -- Parent/Advocate; SSAID (Student Services for American Indians with Disabilities) Southwestern Institute -- Advisory Committee; starting or maintaining parent/family support groups; public speaking; training parents, health care providers, and teachers; promoting legislation
Related Employment: Parent Trainer, *EPICS Project

Donna Naclerio
955 Zuni Court, S.E.
Rio Rancho, NM 87124
505 247-0321
505 892-5728

Children's Disabilities: Learning disability (06/06/77); Mental retardation; autism (06/24/78); Cerebral palsy; asthma; bronchopulmonary dysplasia (06/27/85); Down syndrome; visual and hearing impairments (01/19/87); Cerebral palsy; seizure disorder; microcephaly; gastrostomy tube; oxygen dependent (06/27/86)
Affiliations: *Parents Reaching Out (PRO); Medically Fragile Children's Program; University of New Mexico -- Parent Advisory Board; Department of Human Services -- Baby Doe Task Force
Care Facility: West Mesa Pediatrics and University of New Mexico Hospital -- Albuquerque, NM
Skills and Interests: Advocating for services for medically fragile, multi-handicapped children; issues for adoptive parents; advocacy for children with special needs in need of adoption
Experience: Conducting training sessions for parents, health care providers, and teachers; promoting legislation; starting or maintaining support groups; providing outreach to families whose children with disabilities are in crisis or in danger of out-of-home placement; working with foster families and multi-handicapped and medically fragile children; advocating for these children's medical and educational programs; providing training for other service providers
Related Employment: Social Worker, ARC of Albuquerque, NM

Elizabeth Padilla
P.O. Box 305
Tome, NM 87060
505 865-5967

Child's Disabilities: Chronic renal failure (08/16/74)
Affiliations: Medically Fragile Program of New Mexico -- Parent Member
Care Facility: University of New Mexico Hospital -- Albuquerque, NM; UCLA Medical Center -- Los Angeles, CA
Skills and Interests: Teaching Special Education at the CD-D level
Experience: University of New Mexico Hospital Parent Advisory Board Member
Related Employment: Special education teacher
Languages other than English: Spanish

Leau A. Phillips
2120 Valencia, N.E., #3
Albuquerque, NM 87110
505 842-9045
505 268-2564

Child's Disabilities: Deafness/blindness; microcephaly (04/24/82)
Affiliations: *Parents Reaching Out (PRO); Deaf/Blind Parent Support Group
Care Facility: Presbyterian Hospital -- Albuquerque, NM
Skills and Interests: Specific programming in schools for children with deafness/blindness
Experience: Starting or maintaining parent/family support groups; public speaking; promoting legislation
Related Employment: Parent Liaison, *Parents Reaching Out (PRO)

Rosemary Silversmith
P.O. Box 323
Crownpoint, NM 87313
505 786-5639

Child's Disabilities: Hearing impairment; developmental delay; undeveloped lower intestines (06/17/81)
Affiliations: Navajo Nation Council -- Treasurer, Handicapped Board -- Window Rock, AZ
Care Facility: Crownpoint Indian Health Services -- Crownpoint, NM; Santa Fe Indian Health Hospital -- Santa Fe, NM
Skills and Interests: Talking with parents who need to become familiar with their rights, the laws, special education process, keeping records, and acceptance of their child's condition
Experience: Involved in grant requesting to have Arizona, Utah, and New Mexico develop a family-centered, coordinated Early Intervention Systems for Navajo families and children, provide training in the Navajo language to parents of children with special needs; starting or maintaining parent/family support groups; public speaking; training parents, health care providers, or teachers; promoting legislation
Related Employment: Part-time Parent training consultant, Crownpoint Chapter (local community chapter)
Languages other than English: Navajo

Lawrence and Mary Singer
Route 1, Box 472
Espanola, NM 87532
505 753-7237

Child's Disabilities: Down syndrome (07/08/81)
Affiliations: *EPICS Project
Care Facility: Santa Clara Pueblo Clinic -- Santa Clara Pueblo, NM; PHS Hospital -- Santa Fe
Skills and Interests: Early intervention
Experience: Interagency Coordinating Council for 99-457; Parent Advisory Committee; promoting legislation
Languages other than English: Tewa

Cathie Thomas
870 Navajo Lane, S.E.
Rio Rancho, NM 87124
505 266-8811
505 891-2409

Children's Disabilities: Bronchopulmonary dysplasia; ventricular septal defect; paralyzed vocal cord; seizure disorder; Down syndrome; allergies to medications; A second child with Bronchopulmonary dysplasia; hydrocephalus; A third with Bronchopulmonary dysplasia; pulmonary hypertension; chronic obstructive restrictive airway disease; neurological growth disorder; vision impairment
Affiliations: *Parents Reaching Out (PRO); School of Medicine, University of New Mexico Hospital -- Parent Advisory Board; Association for Retarded Citizens of Albuquerque;

Companion Home Program; Medically Fragile Children's Program -- Advisory Board
Care Facility: Children's Hospital of New Mexico, University of New Mexico Hospital, and Presbyterian Hospital -- Albuquerque, NM
Skills and Interests: Support for families with medically fragile children; adoption/foster care; recruiting for children with special needs; training adoption and foster care staff; infant development specialist
Experience: Preschool for Intensive Needs Infants and Preschoolers -- Teacher; Medically Fragile Children's Program Task Force; public speaking; leading training for health care providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments; working on hospital's parent advisory group
Related Employment: Social worker; Special Education Teacher for intensive needs infants and preschoolers

Trish Thomas
P.O. Box 1387
Old Laguna, NM 87026
505 867-3396
505 552-9889

Child's Disabilities: Hearing and visual impairments
Affiliations: *EPICS Project -- Parent Trainer; Laguna Special Needs Parent Group; *Parents Reaching Out (PRO) -- Parent Group; Community-Based Coordination of Care Project, Southwest Communication Resources, Inc. -- Parent Advocate
Care Facility: Indian Health Service, ACL Hospital -- San Fidel, NM; Eye Associates of New Mexico -- Albuquerque, NM
Skills and Interests: Early intervention; cultural sensitivity
Experience: New Mexico Procedural Safeguards Committee for P.L. 99-457; New Mexico Long-range Task Force for P.L. 94-142; New Mexico P.L. 99-457 Part H Model Projects -- Family Specialist; starting or maintaining parent/family support groups; public speaking; training health care providers and teachers; promoting legislation
Related Employment: Parent Advocate, SCRCBCC Project; Training Consultant, SCR Pathways to Communication Project

Jennifer Kay Thorne
5520 Granite, N.E.
Albuquerque, NM 87110
505 827-2581
505 265-3650

Children's Disabilities: Communication disorder; apraxia (09/28/81); Learning disability; gifted (01/16/78)
Affiliations: *Parents Reaching Out (PRO)
Skills and Interests: Early intervention with integration of all ages
Experience: 99-457 State Interagency Coordinating Council -- past Member; 94-142 State Advisory Panel; participated in several task forces related to state legislative memorials; starting or maintaining parent/family support groups; public speaking; training parents and teachers; promoting legislation
Related Employment: Planner for lead agency for P.L. 99-457, Part H, Developmental Disabilities Division

Sally Van Curen
23 Goodheart Road
Los Lunas, NM 87031
505 842-9045
505 865-0955

Child's Disabilities: Cerebral palsy (03/13/80)
Affiliations: New Mexico Protection and Advocacy; *Parents Reaching Out (PRO) -- Executive Director
Care Facility: Private physician
Skills and Interests: All areas of family support
Experience: Directing a project that provides families with support, education, and information; working with CMS of the state health department around issues of care coordination; starting or maintaining parent/family support groups; public speaking; training parents, health care providers and teachers; promoting legislation
Related Employment: Executive Director, *PRO

NEW YORK

Lucinda Barker
119 Carlisle Street
Syracuse, NY 13208

Child's Disabilities: Alpha-1-antitrypsin deficiency (liver disease); labeled emotionally disturbed (11/02/75)

Affiliations: Parents' Network -- Parent Trainer; New York State Developmental Disabilities Planning Council
Care Facility: Upstate Medical Center -- Syracuse, NY
Skills and Interests: Networking with parents before and after their child enters the special education system
Experience: Developing parent training workshops; starting or maintaining parent/family support groups; public speaking; training parents; promoting legislation

Hilary Blake
117 Winston Drive
Ithaca, NY 14850
607 273-7013

Child's Disabilities: Oral dyspraxia; dysphasia; attention deficit disorder (08/26/77)
Affiliations: Down Syndrome Association; Learning Disabilities Association
Care Facility: Private pediatrician
Skills and Interests: Foster care/adoption; respite care; health care financing; early intervention; parent and family support (particularly for parents of young children)
Experience: Starting or maintaining parent/family support groups; public speaking; promoting legislation
Related Employment: Parent coordinator, 99-457 Regional Planning Group for Early Intervention
Languages other than English: Spanish

Mary Bonsignore
210 West 251st Street
Bronx, NY 10471
212 519-4797
212 548-3825

Child's Disabilities: Rubella syndrome; mental retardation; profound hearing loss; cerebral palsy (10/01/64)
Affiliations: UTOPIA (United Today To Organize Parents of Impaired to Action) -- President and Co-founder; Community Board #8 -- Health, Hospital, and Social Services Committee Chairperson; Bronx Mental Retardation Council -- Executive Board Member and Family Support Committee Chairperson
Care Facility: Montefiore Medical Center, Department of Family Medicine -- Bronx, NY
Skills and Interests: Increasing public awareness; parent-to-parent support; early intervention with families; parent/professional collaboration
Experience: Public speaking; conducting training sessions for health care providers/medical students; promoting legislation; planning and developing conferences; starting or maintaining support groups; religious outreach; working with the state Office of Mental Retardation and Developmental Disabilities
Related Employment: Parent Peer Counselor, Newborn and Family Support Project for the Developmentally Disabled, North Central Bronx Hospital -- Bronx, NY

Margaret V. Bordonaro
14 Poplar Circle
Peekskill, NY 10566
914 737-7233

Child's Disabilities: Craniosynostosis (07/31/88)
Affiliations: International Craniofacial Foundations -- Parental Advisory Board Member; an advocacy group for parents of children with craniofacial anomalies -- Co-chair
Care Facility: Montefiore Medical Center -- Bronx, NY
Experience: Starting or maintaining parent/family support groups; public speaking; promoting legislation

Marie Capobianco
17 Kraemer Street
Hicksville, NY 11801
515 931-6338

Child's Disabilities: Mucopolysaccharidosis; mucolipidosis
Affiliations: National MPS Society, Inc. -- President and Contact Person
Experience: Organizing national parent group focused on mucopolysaccaroid and mucolipid diseases

Joan and Jeremy Chess
722 Cove Road, E.
Mamaroneck, NY 10543

Child's Disabilities: Autism; Rett syndrome (03/26/85)
Affiliations: Autism Society -- Westchester

Chapter; International Rett Syndrome Association
Care Facility: Private physician
Skills and Interests: Respite; early intervention
Experience: Local school district's special education program development; starting or maintaining parent/family support groups
Related Employment: Joan -- School Psychologist, Mamaroneck School System; Jeremy -- Ophthalmologist

Paul and Judy T. Essex
Route 1 Box 21
Neversink, NY 12765
914 794-3300
914 985 7775

Child's Disabilities: Spina bifida
Affiliations: Parents of Challenged Children -- Founder; Sullivan Diagnostic and Treatment Center -- Board Member
Care Facility: New York Hospital, Cornell Medical Center -- New York, NY
Skills and Interests: Serving on Town Handicapped Committee
Experience: Public speaking; conducting training sessions for health care providers/teachers; promoting legislation; starting or maintaining support groups; health planning; Community General Hospital of Sullivan County -- former Grants Specialist, Health Care Administration; CGH Center for Health Promotion -- former Assistant Planner and Coordinator
Related Employment: Director of Home Care, Cornell Cooperative Extension of Sullivan County

Dawne Flammger
14 Leawood Drive
Tonawanda, NY 14150
716 695-8007

Children's Disabilities: First child with diaphragmatic hernia; mild cerebral palsy; Second child born premature
Affiliations: AGAPE -- Parent Fellowship Director
Care Facility: Children's Hospital -- Buffalo, NY
Skills and Interests: Parent-to-parent support; training for medical students; developing respite care facility; systems for telephone support
Experience: Public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups

Christina C. Fox
125 Northmore Drive
Yorktown Heights, NY 10598
914 962-3326
914 245-0398

Child's Disabilities: Hirschsprung's disease (02/28/79)
Affiliations: Parents for Parents, Inc. -- Founder and Executive Director; American Hirschsprung's Disease Association
Care Facility: Babies' Hospital, Columbia-Presbyterian Medical Center
Skills and Interests: Supporting parents with ill or hospitalized children
Experience: Organizing Parents for Parents, Inc. (support group for parents of ill or hospitalized children); holding monthly meetings at three New York City area hospitals; starting or maintaining parent/family support groups; public speaking; training parents and health care providers
Related Employment: Special education teacher

Margaret Mikol
990 2nd Avenue
New York, NY 10022
212 421-9160

Child's Disabilities: Ventilator dependence (deceased)
Affiliations: SKIP of New York -- Director of Programs
Care Facility: New York Hospital -- New York, NY
Skills and Interests: Family advocacy
Experience: Public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments
Related Employment: Director of Programs, SKIP of New York

Roberta Longhi Montetta
Cedar Lane Apartments, #A16
Ossining, NY 10562

Child's Disabilities: Brain damage; anoxia; spastic quadriparesis; seizure disorder; gastrostomy tube (12/12/82)
Affiliations: RECOGNIZE, ACCEPT, COMMIT, EMBRACE The Right to Live at Home, Inc. -- Executive Director

Care Facility: Westchester County Medical Center -- Westchester County, NY; Kaiser-Permanente -- Stamford, CT
Skills and Interests: Discharge planning; care coordination; advocating to help keep children with special needs at home and maintain a quality of life for all
Experience: State Interagency Coordinating Council for 99-457 -- Parent Member; RGP District 4 -- Parent Coordinator; starting or maintaining parent/family support groups; public speaking; training parents and health care providers; promoting legislation
Related Employment: Executive Director, RECOGNIZE, ACCEPT, COMMIT, EMBRACE The Right to Live at Home, Inc.

Claudia and Ed Pagani
32 Dearborn Lane
Spencerport, NY 14559
716 352-3170

Child's Disabilities: Central hypoventilation syndrome; diaphramatic pacer (1984)
Affiliations: Ed -- Birth to Three Network; NY State ICC -- Co-chair; Strong Memorial -- Pediatric Pulmonary Advisory Council
Care Facility: Strong Memorial -- Rochester, NY; Presbyteria -- Chicago, IL; Massachusetts General -- Boston, MA
Skills and Interests: Early intervention; child care; respite care for children with technology dependence
Experience: Starting or maintaining parent/family support groups; public speaking; training parents, health care providers, and teachers; promoting legislation; nursing personnel preparation for children with high technology

Dorothy Stone
3801 Hudson Manor Terrace
Bronx, NY 10463
212 519-4797
212 549-2768

Child's Disabilities: Cerebral palsy (spastic quadriplegia); moderate mental retardation; speech impairment (09/20/60)
Affiliations: UTOPIA (United Today to Organize Parents of Impaired to Action) -- Co-founder and Board Member; Special Friends Program of Hebrew Institute of Riverdale -- Co-founder and Advocate; Association for the Help of Retarded Children (A.H.R.C.) -- Family Education Committee, New York City Chapter
Care Facility: Health Insurance Plan (HIP), Washington Heights Group (general care) and Cerebral Palsy Clinic, Hospital for Special Surgery (specialized care) -- New York, NY
Skills and Interests: Parent-to-parent support; parent/professional collaboration; early intervention; parent training, information, and referral
Experience: Public speaking; conducting training sessions for health care providers/teachers; promoting legislation; starting or maintaining support groups; advocating for families of children with multiple handicaps; New York State Developmental Disabilities Planning Council; New York State Office of Mental Retardation/ Developmental Disabilities Day Services Committee
Related Employment: Project Coordinator, Newborn and Family Support Project for the Developmentally Disabled, North Central Bronx Hospital -- Bronx, NY

Frances Walsh
202 Tamarck Lane
Brewster, NY 10509
914 279-8382

Child's Disabilities: Craniosynostosis (08/20/88)
Affiliations: Montefiore Medical Center -- Co-founder, Parents Advocacy Group for Craniofacial Anomalies
Care Facility: Montefiore Medical Center -- Bronx, NY
Skills and Interests: Early intervention; proper diagnosis of children with craniofacial anomalies
Experience: Parent/professional collaboration to increase public awareness and get help for children who suffer from lack of treatment; starting or maintaining parent/family support groups; public speaking

NORTH CAROLINA

Anne B. Gildea
1506 Double Oaks Road
Greensboro, NC 27410

Child's Disabilities: Cerebral palsy; mental retardation
Skills and Interests: Parent educational advocacy and networking

Experience: Founder and chairperson of a Maryland parent support program; currently program coordinator for a parent-to-parent support program in North Carolina
Related Employment: Special Education Teacher

Frank Graziadei
6915 Dulverton Drive
Charlotte, NC 28226
704 595-6123
704 365-1219

Children's Disabilities: One child with Duchenne muscular dystrophy; Second child with learning disabilities
Affiliations: Exceptional Children's Assistance Center -- Executive Committee; Catholic Diocese of Charlotte -- Steering Committee for Persons with Disabilities; Carolina Computer Access Center -- Director
Care Facility: Charlotte Rehabilitation Center -- Charlotte, NC
Skills and Interests: Educating professionals who work with families with exceptional children; parent/professional collaboration
Experience: Muscular Dystrophy Association, South Piedmont Chapter -- past President; public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments

Joanne Mackey
213 Haverhill Drive
Fayetteville, NC 28304
919 868-1408

Children's Disabilities: Asthma (05/02/79); Spina bifida; hydrocephalus (04/04/78)
Affiliations: Parents Helping Parents; Spina Bifida Association of South Central North Carolina -- Treasurer; Association of Developmental Day Directors; ACCH
Care Facility: Duke University Medical Center -- Durham, NC
Skills and Interests: Parent-to-parent support; legislative action for children with chronic illness; advocacy for implementation of P.L. 99-457; financing health care; administration of programs
Experience: Spina Bifida Association of South Central North Carolina -- Grant and Legislative Liaison; public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; promoting parent/professional collaboration; serving on Parent Advisory Committee to the Maternal and Child Health Section, North Carolina Department of Environment, Health, and Natural Resources
Related Employment: R.N.; Director, UCP Developmental Day Center

Brenda Potter
510 Danie Street
Wilmington, NC 28401

Child's Disabilities: Interstitial 2q Minus (genetic abnormality); profound mental retardation; Cerebral palsy quadriplegia; cortical blindness; hearing impairment; intractable seizure disorder; gastroesophageal reflux; gastrostomy tube feedings; scoliosis; bilateral hip dislocation (08/16/72 to 05/15/90)
Affiliations: Parents Supporting Parents -- Board Chairwoman and former Program Coordinator; New Hanover Memorial Hospital -- Infant Care Review Committee; United Cerebral Palsy Advisory Council -- former Chairwoman; United Cerebral Palsy of NC -- former Board Member; Advisory Board on Education for Children with Special Needs, New Hanover County Board ofEducation -- former Member
Care Facility: East Carolina University Medical Center -- Greenville, NC
Skills and Interests: Respite care; day care; parent/professional collaboration; parent child interaction (NCAST); group homes; changing societal attitudes toward people with disabilities through puppetry
Experience: Working with the county school system; working with the state health department's child specialty health care clinics, neonatal intensive care follow-up, and high priority infant tracking; starting or maintaining parent/family support groups; public speaking; training health care providers and teachers; promoting legislation
Related Employment: Pediatric Nurse Practitioner, Developmental Evaluation Center; Consultant, Respite Home

Sandy Steele
Parents Supporting Parents
DEC, Irons Building, ECU Campus
Greenville, NC 27858
919 757-4494
919 355-3127

Child's Disabilities: Down syndrome
Affiliations: Parents Supporting Parents (PSP)

-- Coordinator; DownEast Down Syndrome Support Group; ARC
Care Facility: Greenville Pediatrics; Developmental Evaluation Clinic (physical & occupational therapy); Pitt County Children's Hospital
Skills and Interests: Fundraising for higher education and non-profit groups
Experience: Starting or maintaining parent/family support groups in community (just starting program in hospital)
Related Employment: Coordinator, Parents Supporting Parents

Beth Stewart
3531 South Jim Minor Road
Haw River, NC 27258
919 684-3401 -- Duke Pediatric Hematology
919 578-5038

Child's Disabilities: Cancer (rhabdomyosarcoma) (08/25/77)
Affiliations: North Carolina Children and Youth Section -- Parent Advisory Council; ACS Statewide Pediatric Oncology Subcommittee; Candlelighters Childhood Cancer Foundation -- Board Member; ACCH -- Board Member
Care Facility: Duke University Medical Center -- Durham, NC
Skills and Interests: Parent support; pediatric hospice care; state-wide parent networking; sibling support and education for siblings; parent/professional collaboration; educating professionals; family-centered care; service/care coordination
Experience: Public speaking; conducting training sessions for health care providers or teachers; starting or maintaining support groups; developed handbook for parents of children with cancer; participated in the ACCH family-centered care film; ACCH 1988 Leadership Forum Member; Fall/Winter 1988-89 CNC Journal -- Guest Editor
Related Employment: R.N.; M.S.N.; Clinical Nurse Specialist, Pediatric Hematology/Oncology, Duke University Medical Center

Gladys and Ben Whitehouse
5007 Lancaster Road
Greensboro, NC 27410
919 547-0573

Child's Disabilities: Down syndrome (06/20/87)
Affiliations: Parent-to-Parent Support; Parents of Children with Down Syndrome
Care Facility: Kendall Center -- Greensboro, NC
Experience: Advisory Board for Parent-to-Parent; Gladys -- Interagency Coordinating Council; Ben -- Dad's Group -- Facilitator; starting or maintaining parent/family support groups; public speaking; training parents, health care providers, or teachers
Languages other than English: Gladys -- Spanish

Val Wilson
509 West Aycock Street
Raleigh, NC 27608
919 856-7774
919 832-3883

Children's Disabilities: Premature twins (28 week gestation)
Affiliations: North Carolina Project 0-3 Task Force; Parent-Care; Raleigh Mother of Twins Club; PTA
Care Facility: Wake Medical Center -- Raleigh, NC
Skills and Interests: Information on twins, prematurity, and child development; parent-to-parent support
Experience: Public speaking; conducting trainingsessions for health care providers or teachers; starting or maintaining support groups; conducting training sessions for parents in communication skills and parent-to-parent support; working with state health and education departments on early intervention and infant development issues
Related Employment: Parent-Infant Resource Specialist and Training Coordinator, Project Enlightenment -- Raleigh, NC

NORTH DAKOTA

Katherine Erickson
*Pathfinder Services of North Dakota
1600 2nd Avenue, S.W.
Minot, ND 58701
701 852-9426
701 838-9324 (fax)

Child's Disabilities: Multiple disabilities resulting from rubella (04/65)
Affiliations: *Pathfinder Services of North Dakota -- Project Director; North Dakota

Department of Human Services Advisory Board; Minot Air Force Base -- Exceptional Family Member Program Review Committee; *Pathfinder Services of North Dakota -- Executive Director
Skills and Interests: Law and procedure; integration of children with special needs; young adult transition planning; communication and self-advocacy
Experience: Serving on steering committees for the North Dakota Department of Special Education; starting or maintaining parent/family support groups; public speaking; training parents, providers, and teachers
Related Employment: Project Director, *Pathfinder Services of North Dakota

OHIO

Dorothy Arlt
ACT on Disabilities Inc.
618 Second Street, Suite 105
Canton, OH 44703
216 455-8806

Child's Disabilities: Learning disability (health related) (03/07/70)
Affiliations: ACT on Disabilities Inc.
Care Facility: Medical Clinic -- North Canton, OH
Skills and Interests: Early Intervention Collaborative -- Centralized Intake & Referral
Experience: EIG; ACLD; Health planning; starting or maintaining parent/family support groups; public speaking; training parents, health care providers, or teachers; promoting legislation
Related Employment: Parent advocate and Director, ACT on Disabilities Inc.

Candee Basford
320 Buck Run
Seaman, OH 45679
513 393-1904
513 695-0619

Child's Disabilities: Down syndrome (11/19/78)
Affiliations: Down Syndrome Association; Parents of Children with Special Needs; *Ohio Coalition for Education of Handicapped Children
Care Facility: Peebles Family Health Center -- Peebles, OH; Children's Hospital -- Cincinnati, OH
Skills and Interests: Integration
Experience: Hopewell Special Education Regional Resource Center -- Parent Advisory Council Member; MRDD School -- former Board Member; starting or maintaining parent/family support groups; public speaking; training parents, health care providers, or teachers
Related Employment: Parent Consultant, Hopewell Special Education Regional Resource Center

Jennifer Brown
3747 Renoir Place
Cincinnati, OH 45241
513 563-0753

Child's Disabilities: Autism; mental retardation (08/74)
Affiliations: Autism Society of Cincinnati -- past President; ARC of Hamilton County -- Vice President; *SOC
Skills and Interests: Respite care
Experience: Working with the local school district; starting or maintaining parent/family support groups; public speaking; training parents, health care providers, and teachers

Kimberly A. Duke
614 3rd Street, N.W., #4
Canton, OH 44703
216 455-8806

Child's Disabilities: Muscular dystrophy (08/90)
Affiliations: MDA Support group; ACT on Disabilities Inc.
Care Facility: Akron Children's Hospital -- Akron, OH
Skills and Interests: Transporting children to school

Jackie and Bob Ellerbrock
Route 2 Box 175
Continental, OH 45831
419 596-4598

Child's Disabilities: Diastrophic dwarfism; tracheomalacia; scoliosis; kyphosis; cleft palate; club foot; hearing loss; reactive airway disease (07/19/85)
Affiliations: LPA (Little People of America)
Care Facility: Minneapolis Children's Medical

Center -- Minneapolis, MN; St. Josephs Hospital -- Towson, MD; The Toledo Hospital -- Toledo, OH; St. Rita's Hospital -- Lima, OH
Skills and Interests: Financing; home care; early intervention; mainstreaming; integration
Experience: Serving on Local Collaborative Group; starting or maintaining parent/family support groups; public speaking

Carol Farris
1063 Quilliams Road
Cleveland Heights, OH 44121
216 795-7100
216 381-8936

Child's Disabilities: Congential muscular dystrophy; scoliosis; developmental delay (09/27/81)
Affiliations: Achievement Center for Children -- Parent Support Co-leader; Ohio League for the Mentally Retarded; SKIP Regional Coordinating Families
Care Facility: Rainbow Babies and Children -- Cleveland, OH
Skills and Interests: Parent-to-parent support and advocacy; Lekotek programs; parent/professional collaboration
Experience: Public speaking; starting or maintaining support groups; promoting legislation
Related Employment: Lekotek Leader, Achievement Center for Children

Walter and Elaine Hackett
2512 Canterbury Avenue
Cincinnati, OH 45237
513 351-8519
606 491-2464

Child's Disabilities: Mental retardation; hearing impairment (03/09/66)
Affiliations: Southwest Ohio Supporters of Mildly Retarded Adults -- former President; Specialink (a computer resource center enabling the disabled through technology) -- Founders and Directors
Care Facility: University of Cincinnati Family Medical Center, ENT Associates -- Cincinnati, OH
Skills and Interests: Early intervention using technology
Experience: Augmentative and Alternative Communication Task Force; designing programs using technology; starting or maintaining parent/family support groups; public speaking; training parents, health care providers, and teachers; promoting legislation
Related Employment: Specialink (volunteer basis); General Electric Systems Analyst

Janet Hawes
13240 Sandusky, S.W.
Beach City, OH 44703
216 455-8806
216 359-5178

Child's Disabilities: Spina bifida (09/17/69)
Affiliations: Spina Bifida Association of America -- former Board Member and Committee Chair; ACT on Disabilities Inc. -- Information consultant; Ohio Spina Bifida Coalition -- State Group Chairperson; Canton Spina Bifida Association; Ohio DD Alliance for Service Eligibility -- OSBC Delegate; Ohio Department of Health, Division of Maternal & Child Health -- Myelo Committee Representative and former Parent Representative
Care Facility: Aultman Hospital -- Canton, OH
Skills and Interests: Support groups; information and referral; early intervention; financing health care; improving health care and educational, vocational, and adult residential services
Experience: Ohio Spina Bifida Coalition Infant Support Network Project -- Director; developed parent packet; starting or maintaining parent/family support group; public speaking; training parents and teachers; promoting legislation
Related Employment: Information consultant, ACT on Disabilities Inc.
Languages other than English: Spanish

Mr. and Mrs. John B. Hedge
361 Rye Gate
Bay Village, OH 44140
216 835-1968

Child's Disabilities: Acquired aplastic anemia (08/24/72)
Affiliations: Aplastic Anemia Foundation of Northern Ohio -- President; Aplastic Anemia Foundation of America -- Regional Coordinator
Care Facility: Rainbow Babies and Children's Hospital -- Cleveland, OH
Skills and Interests: Developing broader support services for families of children with aplastic anemia

Experience: Starting or maintaining parent/family support groups; public speaking
Related Employment: Former teacher

Beverly Houston
3309 East 118th Street
Cleveland, OH 44120
216 381-1023

Child's Disabilities: Cerebral palsy; visual impairment; seizure disorder; mental retardation (12/28/79)
Affiliations: Epilepsy Foundation of Northeast Ohio; Cleveland Society for the Blind; Parents of Disabled Children; ACCH; Interlink
Care Facility: Rainbow Babies and Children's Hospital -- Cleveland, OH
Related Employment: Dental Health Professional

Jennifer Jackson
432 Binns Boulevard
Columbus, OH 43204
614 279-0823

Child's Disabilities: Multiple handicaps; deafness; developmental delay (06/07/80)
Affiliations: Family First (part of Ohio Family Network) -- Grants Manager
Care Facility: Private physician; Columbus Children's Hospital -- Columbus, OH
Skills and Interests: Early intervention
Experience: State Subcommittee of the ICC -- Service Coordinator; Governor's Special Education Advisory Council; Developmental Disabilities Planning Council -- Education Task Force; public speaking; training parents, health care providers, or teachers
Related Employment: Family First; Ohio Curriculum Project

Cynthia Johnson
1228 Cambridge Boulevard
Columbus, OH 43212
614 466-7203
614 488-8801

Child's Disabilities: Down syndrome (04/10/72)
Affiliations: ODMRDD -- Chief of Office of Family and Child Services; Birth to Three Network; State ICC for Part H; National Down Syndrome Congress; Council for Exceptional Children; TASH; ARC/Ohio
Care Facility: Private physician
Skills and Interests: Early intervention; health care financing; health care issues for adult children with developmental disorders
Experience: Special Education Resource Center -- State and regional Parent representative to Board; personnel preparation in early intervention; helping parents involved in training; starting or maintaining parent/family support groups; public speaking; training parents, health care providers, and teachers; promoting legislation
Related Employment: Chief of Office of Family and Child Services, ODMRDD

Carol Lichtenwalter
Association for Retarded Citizens
618 Second Street, N.W., Suite 10
Canton, OH 44703
216 453-2727
216 833-8836

Child's Disabilities: Down syndrome (01/23/80)
Affiliations: ARC -- Administrative Assistant; U.P.S. for Down Syndrome -- Volunteer coordinator; E.S.D. (Perry Local Schools -- Special education support) -- Coordinator; ACT on Disabilities Inc.
Care Facility: Aultman Hospital -- Canton, OH; Blick Clinic and Akron Children's Medical Center -- Akron, OH
Skills and Interests: Integration
Experience: Ohio Department of Mental Retardation/Developmental Disabilities -- Family Support Coalition; ARC/Ohio -- Family Network; starting or maintaining parent/family support groups; public speaking; promoting legislation
Related Employment: Administrative Assistant, ARC/Stark County

Lynda Macha
203 Miles Road
Chagrin Falls, OH 44022
216 721-8300
216 247-3676

Child's Disabilities: Cerebral palsy; asthma; esophageal reflux (12/18/81)
Affiliations: Achievement Center for Children; SKIP of Ohio; *Ohio Coalition for the Education of Handicapped Children
Care Facility: Mt. Sinai Hospital -- Cleveland, OH

Skills and Interests: Service coordination forfamilies; mainstreaming; early intervention; information and referral
Experience: Achievement Center for Children -- Gund Education Committee; public speaking; parent and professional training (Family First, Building Family Strengths, Parent/Educator Training, Family Ties); service coordination
Related Employment: INTERLINK: Achievement Center for Children -- Service Coordination for Families who have Children with Special Needs

Becky Millsap
7370 Elson Street
Waynesburg, OH 44688
216 866-5242

Child's Disabilities: Autism; hyperactivity (04/25/84)
Affiliations: ADD Support Group; Helping to Support Other Parents; ACT on Disabilities Inc.
Care Facility: Private physician
Skills and Interests: Early intervention; finding care for others
Experience: Designed training programs; starting or maintaining parent/family support groups; public speaking; training parents, health care providers, or teachers
Related Employment: Advocate

Cindy Norwood
3720 Warrensville Center Road, #201
Shaker Heights, OH 44122
216 283-6525

Child's Disabilities: Complex health care needs (06/16/83)
Affiliations: Birth to Three Network; SKIP of Ohio -- Executive Director; Governor's Early Intervention Council; Family Information Network -- Consultant; Rainbow Babies and Childrens Hospital -- Family Advisory Committee
Care Facility: Rainbow Babies and Childrens Hospital -- Cleveland, OH
Skills and Interests: Respite care; health care financing; early intervention; parent/professional relationships
Experience: ICC; Parent Advisory Committees; starting or maintaining parent/family support groups; public speaking; training parents, health care providers, and teachers; promoting legislation
Related Employment: Consultant
Languages other than English: Sign language

George and Bobbie Sich
4815 Carlow Circle
Middletown, OH 45042
513 423-0243

Child's Disabilities: Spina bifida (09/25/74)
Affiliations: Spina Bifida Association of Cincinnati; Ohio Spina Bifida Coalition -- Secretary; Middletown City Schools -- Parent Advisory Council for Special Education; Spina Bifida Association of America; Cincinnati Center for Developmental Disabilities -- Board of Trustees
Care Facility: Center for Developmental Disabilities, University of Cincinnati -- Cincinnati, OH
Skills and Interests: Educational issues for children with special needs; parent support and advocacy
Experience: Spina Bifida Association of America -- Vice President, Bylaws Chairperson, and Strategic Planning Chairperson; public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments; conference planning
Related Employment: Speech/language pathologist

OKLAHOMA

Dana Baldridge
2112 Raintree Road
Edmond, OK 73034
405 843-9114
405 348-4569

Child's Disabilities: Cerebral palsy (11/03/74)
Affiliations: Positive Reflections, Inc. -- Co-founder and Director; Planning Council on Developmental Disabilities; Governor's Cabinet Council for Children & Youth
Care Facility: Children's Hospital of Oklahoma -- Oklahoma City, OK
Experience: Organized and co-developed Respite Care Training Curriculum, Emotionally Disturbed Curriculum, and Medically Fragile Curriculum in conjunction with State Department of Vo-Tech; Allied Health -- Mid-Del Vo-Tech -- Advisory Committee; Special Education, State Department of Education -- EHA-B Subcommittee; starting or

maintaining parent/family support groups; public speaking; training parents and health care providers; promoting legislation
Related Employment: Director, Positive Reflections, Inc.

Sharon Bishop
1301 Glen Oaks Court
Norman, OK 73107
405 681-9710

Child's Disabilities: Cerebral palsy (10/25/69)
Affiliations: United Cerebral Palsy of Oklahoma -- Assistant Director; PRO-Oklahoma -- Director
Skills and Interests: Advocacy; parent training in P.L. 94-142; communication skills; supported employment; transition; early childhood 0 to 5
Experience: Committee Interagency Coordinating Council for 99-457; Oklahoma Special Education Assistive Technology Committee; Self-Advocacy(People First) Conference Committee; Special Education, State Department of Education -- EHA-B Subcommittee; starting or maintaining parent/family support groups; public speaking; training parents, health care providers, or teachers; promoting legislation
Related Employment: Assistant Director, United Cerebral Palsy of Oklahoma; Director, PRO-OK

Rita A. Kukura
3720 East 43rd Street
Tulsa, OK 74135
918 744-1000, ext. 3302
918 745-0404

Child's Disabilities: Tourette syndrome; significant brain dysfunction; hyperactivity; attention deficit disorder (07/29/78)
Affiliations: Tourette Syndrome Association -- President of OK Chapter; Friends of Special Children; ACCH; Parent to Parent of Florida; Tulsa Ronald McDonald House -- Resource Development Committee
Care Facility: Center Family -- Tampa, FL
Skills and Interests: Services for children with special needs and their families; early intervention
Experience: Certified Family Life Educator; Tulsa Council for Needs of Special Children; Coordinate for Kids -- Consultant; Family Support Project Outreach Program -- Consultant and State Family Coordinator for the outreach program; starting or maintaining parent/family support groups; parent training
Related Employment: Consultant, Family Outreach Program, Pediatric Division, Oklahoma State Department of Health; Regional Coordinator, Early Intervention (Part H) Program ("Sooner Start") for Tulsa County

Preston McPhail
38 Southwest 49th
Lawton, OK 73505
405 357-4271
405 581-5281

Child's Disabilities: Neuroblastoma (12/23/80 to 1984)
Affiliations: March of Dimes -- Board Member; OKlahoma Family Support Task Force
Care Facility: Oklahoma Children's Memorial Hospital -- Oklahoma City, OH
Skills and Interests: Legislative and policy making; respite care
Experience: Starting or maintaining parent/family support groups; public speaking; training parents; promoting legislation

Kathy S. Stephens
7427 East 67th Place
Tulsa, OK 74133
918-254-5433

Children's Disabilities: Two children with C-Syndrome
Affiliations: Positive Reflections; Tulsa Association for the Retarded
Care Facility: St. Francis Hospital -- Tulsa, OK
Skills and Interests: Funding Committee Co-chair; Family Committee Member for a Special Task Force for Oklahoma working on P.L. 99-457
Experience: Public speaking; conducting training sessions for health care providers or teachers; promoting legislation; maintaining support groups; working with the state on implementation of P.L. 99-457; working with the state health department to help coordinate MCH grants
Related Employment: Project Director, Friends of Special Children, Inc.

OREGON

Elsie Edge
9915 Southwest Killarney Lane
Tualatin, OR 97062
503 692-6157

Children's Disabilities: One child with encephlocele; hydrocephalus; developmental delay; Another with severe head injury
Affiliations: Pilot Parents
Care Facility: Emanuel Hospital -- Portland, OR
Skills and Interests: Parent support and advocacy; networking at county and state level for continuum of education services; early intervention
Experience: Oregon Zero to Three Project -- Parent Representative; public speaking; participated in training for health providers/teachers

Pam Kourafas
2612 Southwest Tegart
Gresham, OR 97030
503 234-9991

Child's Disabilities: Tuberous sclerosis
Affiliations: Association for Severely Other Health Impaired (ASOHI) -- Treasurer
Skills and Interests: Increasing educational options; issues and services for children with chronic illness; parent/professional partnerships
Experience: Leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments

Cheron J. Mayhall
761 55th Avenue, N.W.
Salem, OR 97304
503 373-7477
503 399-7966

Children's Disabilities: Juvenile diabetes (05/11/79); Deafness (12/23/77); Learning disabilities (perceptual and motor) (04/17/71)
Affiliations: *Oregon COPE Project -- Executive Director; Oregon Society for Deaf Children -- Co-founder and past President; American Society for Deaf Children; American Diabetes Association/Oregon Affiliate
Care Facility: Pediatric Clinic -- Salem, OR
Skills and Interests: Parent involvement/partnerships with professionals
Experience: OR State Advisory Council for Special Education -- former Chair; Oregon PTI Advisory Board; Western Regional Resource Center -- Board Member; National Parent Network on Disability (NPND); Very Special Arts/OR -- Board Member; starting or maintaining parent/family support groups; public speaking; training parents, health care providers, or teachers; promoting legislation
Related Employment: Executive Director, *Oregon COPE Project
Languages other than English: Sign Language

Marshall and Susan Peter
2995 Kincaid Street
Eugene, OR 97405
503 461-2212
503 343-6090

Child's Disabilities: Multiply and severely disabled (12/11/80 to 03/02/90)
Affiliations: Coalition in Oregon for Parent Education, University of Oregon University Affiliated Program
Skills and Interests: Community based care; child- and family-centered interagency collaboration; health care financing; family support; parent empowerment; the future of special education and rehabilitation
Experience: Starting or maintaining parent/family support groups; public speaking; training parents and teachers; promoting legislation; community activism
Related Employment: Executive Director, Lane County Direction Service

David and Laura Soyster
424 Northeast Hazelfern Place
Portland, OR 97232

Child's Disabilities: Cerebral palsy (06/12/83)
Affiliations: Multnomah County Early Intervention Advisory Council -- Parent Representative; Parent Advisory Council for Regional Programs -- Parent Representative; State Early Intervention Council
Care Facility: Sylvan Medical Clinic -- Portland, OR
Skills and Interests: Early intervention

Experience: Serving on the county and state Early Intervention Advisory Councils and on the Parent Advisory Council for Regional Programs; starting or maintaining parent/family support groups; training parents; promoting legislation

Becky Venice
138 North H Street
Cottage Grove, OR 97424
503 942-4269

Child's Disabilities: Down syndrome
Affiliations: *Oregon COPE Project -- Regional Consultant; ARC; National Down Syndrome Congress; Oregon Developmental Disabilities Council; Oregon Disabilities Commission
Skills and Interests: Development of independent living opportunities
Experience: Public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups
Related Employment: Regional Consultant, *Oregon COPE Project

PENNSYLVANIA

Kathleen Brehm
363 Highland Avenue
Berwyn, PA 19312
215 647-7870

Children's Disabilities: Asthma; allergies (03/05/83 and 12/14/84)
Care Facility: Allergy & Immunology Clinic -- West Chester, PA
Skills and Interests: School nursing; environmental concerns that impact health
Experience: American Lung Association of Delaware & Chester Counties -- Board Member and Liaison to Delaware Valley Clean Air Council; establishing local group to establish air pollution ordinance; public speaking; training health care providers and teachers; promoting legislation
Related Employment: Part-time School Nurse

Loretta M. Collins
3515 Churchill Lane
Philadelphia, PA 19114
215 242-9501

Child's Disabilities: Cerebral palsy
Affiliations: Parents' Exchange -- Parent Liaison
Care Facility: United Cerebral Palsy Association of Philadelphia -- Philadelphia, PA
Skills and Interests: Public education; community-wide mainstreaming for the child with chronic illness or disabilities
Experience: Public speaking; conducting training sessions for health care providers or teachers; starting or maintaining support groups; working with the state health department, which funds the Parents' Exchange

Judy Dinofrio
934 North Street
Freeland, PA 18224
215 636-3402

Child's Disabilities: Lowe's syndrome (03/17/66)
Affiliations: Lowe's Syndrome Association; Friends of United Rehabilitation Services -- Auxiliary of U.R.S.
Care Facility: St. Christopher's Children's Hospital -- Philadelphia, PA
Experience: Local School District -- Advisory Committee; advocacy; starting or maintaining parent/family support groups; public speaking; training parents, health care providers, or teachers

Linda Dutton
367 Highland
Devon, PA 19333
215 296-8666

Child's Disabilities: Systemic juvenile rheumatoid arthritis (12/18/80)
Affiliations: Parents' Union; American Juvenile Arthritis Organization (AJAO) -- National Executive Committee; Arthritis Foundation -- Chapter Board of Directors; AJAO Philadelphia Area Parent Group -- Founder
Care Facility: Children's Hospital of Philadelphia and Children's Seashore House -- Philadelphia, PA
Skills and Interests: Parent advocacy training; legislative issues; specific issues for children with chronic illnesses
Experience: Working with the state department of education on task force coordinating "504 Rights" to the availability of "related services"; starting or maintaining family/parent support groups; public speaking; training parents and teachers; promoting legislation

Coleen Geyer
564 Hackman Road
Lititz, PA 17543

Child's Disabilities: Down syndrome (06/30/78)
Affiliations: Lancaster County Support Group for Down Syndrome -- Co-founder; Parent Helping Parent Group -- Co-founder; ARC
Care Facility: Lancaster General Hospital and Rosedale Pediatrics -- Lancaster, PA
Skills and Interest: Integration; respite care; sitter services
Experience: Serving on the task force on mental retardation; serving on the Parent Transition Committee for Intermediate Unit in Education; working with the local mental health and mental retardation services; starting or maintaining parent/family support groups; training parents, health care providers, and teachers; promoting legislation

Barbara Ginsburg
1125 Wightman Street
Pittsburgh, PA 15217
412 681-6685

Child's Disabilities: First branchial arch syndrome; mental retardation (01/22/78)
Affiliations: ARC Parent-to-Parent support group; Conroy Education Center; Idlewood Center
Care Facility: John Merck Developmental Disabilities Clinic and Idlewood Center, Carnegie -- Pittsburgh, PA
Skills and Interests: Respite care; early intervention; parent education relating to child development and parenting issues; families' transition from community-based intervention programs to ECH in public schools
Experience: Worked on a transition parent program for three year olds; starting or maintaining parent/family support groups; public speaking; training health providers, parents, and teachers
Related Employment: Parent and Teacher Education Consultant

Cheryl and Richard Goldschmidt
79 South Wycombe Avenue
Landsdowne, PA 19050

Child's Disabilities: Cerebral palsy; mental retardation; seizure disorder; swallowing disorder; stroke post surgery (07/72)
Affiliations: ARC -- Richard -- President, Delaware County Chapter; Kids of the Block Delaware County, PA -- Cheryl -- Coordinator
Care Facility: Children's Hospital of Philadelphia -- Philadelphia, PA
Skills and Interests: Quality respite care
Experience: Public speaking
Related Employment: Cheryl -- Early Childhood Teacher

Page Talbott Gould
440 Bryn Mawr Avenue
Bala Cynwyd, PA 19004

Child's Disabilities: Prematurity (26 weeks gestation); developmental delay (04/17/77)
Affiliations: Intensive Caring Unlimited -- Founder, past President, Advisor, and in charge of development; Parent Care -- Founder, past Vice-President for Development, and Professional Advisory Board Member; Delaware Valley March of Dimes -- Professional Advisory Board Member
Care Facility: The Children's Hospital of Philadelphia -- Philadelphia, PA
Skills and Interests: Fundraising; home care services; parent-to-parent support in the NICU
Experience: Working with the state health department on the MCH Block Grant Advisory Committee; participated in MCH meeting on linkage of services under P.L. 99-457; Family Help, Inc. (home care for maternal, perinatal, and neonatal care groups) -- Advisory Board Member; served as co-chairperson for the national conference of Parent Care; founded support group for parents of premature and high risk infants initially supported by Children's Hospital of Philadelphia, but now a community-based program serving 60 hospitals; program, manual, and resource directory for peer support in the NICU; trained Breastfeeding Counselor (CEA); public speaking; training parents, health care providers, and teachers
Languages other than English: French

Mr. and Mrs. Roger L. Grandy
209 Davidson Drive
Charleroi, PA 15022

Child's Disabilities: Down syndrome (07/22/67)
Affiliations: ARC -- National Board of Directors; ARC of Pennsylvania -- past President and County Chapter Board Member
Care Facility: Private physician; Western Pennsylvania Hospital -- Pittsburgh, PA

Skills and Interests: Job placement for adults who are retarded; reducing waiting list for day care for adults who are mentally retarded
Experience: Serving as Chairperson of the Local Intermediate Task Force; working on health department advisory board; serving on an Adult Retardation Service advisory board; starting or maintaining parent/family support groups; public speaking; promoting legislation

Pam Meyer Kunkle
152 Dickson Avenue
Pittsburgh, PA 19034
412 761-5753

Child's Disabilities: Spina bifida (07/13/76)
Affiliations: Spina Bifida Coalition ofPennsylvania -- Delegate
Care Facility: Allegheny General Hospital -- Pittsburgh, PA
Skills and Interests: Financing; transition services for adolescents; educational advocacy
Experience: Serving on technical advisory group for the state health department regarding needs of children with spina bifida; starting or maintaining parent/family support groups; public speaking; training parents; promoting legislation
Related Employment: School Program Coordinator, Spina Bifida Association of Western Pennsylvania

Suzanne B. Levy
West Chester Psychiatric Associates
1450 Boat Road, Suite 100-A
West Chester, PA 19380
215 431-3575
215 430-0244

Children's Disabilities: Hypothyroidism; cerebral palsy (12/20/82); Hypothyroidism (06/26/84)
Care Facility: A.I. Dupont Institute -- Wilmington, DE
Skills and Interests: Counseling services for families of children with acute or chronic illnesses
Experience: Public speaking
Related Employment: Nurse psychotherapist

Mary Lou Reaver
150 Plunkert Road
Littlestown, PA 17340

Child's Disabilities: Tourette syndrome (11/01/65)
Affiliations: National Tourette Syndrome Association; Pennsylvania Tourette Syndrome Association -- former Local Chapter President; Pennsylvania Protection & Advocacy, Inc. -- Children's Issues Committee and former Board Member; Coalition for Quality in Special Education
Care Facility: Private Physician
Skills and Interests: Education on Tourette syndrome
Experience: Working with the state health department; starting or maintaining parent/family support groups; public speaking; training parents, health care providers, and teachers; promoting legislation
Related Employment: Executive Director, Pennsylvania Tourette Syndrome Association -- Gettysburg, PA

Donna Ross
RD 4 Box 22A
Slippery Rock, PA 16057

Child's Disabilities: Brain damage; cerebral palsy; non-verbal; non-ambulatory; seizure disorder (12/24/66)
Affiliations: Local Task Force to Enforce Right to Education; Association for Retarded Citizens -- Board Member; Advisory Committee Family Support System
Care Facility: United Community Hospital -- Grove City, PA; Private physician
Skills and Interests: Respite care
Experience: Accompanying parents to IEP's; child advocacy; monitoring school districts; starting or maintaining parent/family support groups; public speaking; training parents; promoting legislation
Related Employment: Volunteer

Gail Walker
RD #2
East State Road
Seneca, PA 16346
412 676-8615
412 677-3751

Child's Disabilities: Legally blind; brain injury (06/25/74)
Affiliations: Oil Creek Valley ACLD -- Representative to State Board; Parent's Advisory Council/Local Task Force -- Chairperson

Care Facility: Children's Hospital -- Pittsburgh, PA
Skills and Interests: Early intervention with parents; rural parents; low-income parents
Experience: Starting or maintaining parent/family support groups; public speaking; training parents, health care providers, and teachers; promoting legislation
Related Employment: Project Directory, *Mentor Parent Program

RHODE ISLAND

Helena Gutierrez-Richards
34 Gentian Drive
South Kingston, RI 02879
203 442-0711, ext. 2476
401 783-9293

Child's Disabilities: Leukemia (deceased)
Affiliations: Candlelighters Childhood Cancer Foundation
Care Facility: Rhode Island Hospital -- Providence, RI
Skills and Interests: Parent-to-parent support; grief; loss and bereavement
Experience: Public speaking; leading training for health providers/teachers; starting or maintaining parent/family support groups; working with state health departments; parent consultant
Related Employment: Clinical Social Worker, Oncology Service, Lawrence & Memorial Hospital
Languages other English: Spanish

Patrice A. Richardson
5 Quincy Adamns Road
Barrington, RI 02806
401 245-7189

Children's Disabilities: Cleft lip and palate (01/09/80); Ehlers-Danlos syndrome (10/26/81)
Affiliations: Parents Reaching Out (PRO) of Rhode Island; Ehlers-Danlos National Foundation; National Organization of Rare Disorders (NORD); ACCH
Care Facility: Boston Children's Hospital
Experience: Developing a personal, portable health care record (published by the Division of Family Health, Rhode Island Department of Health); Rhode Island Developmental Disabilities Council -- conducting parent forums; starting or maintaining parent/family support groups; public speaking; training parents, health care providers, or teachers
Related Employment: Staff Nurse, Memorial Hospital of Rhode Island -- Pawtucket, RI

Dawn Wardyga
1 Simmons Road
Barrington, RI 02806
401 245-5241

Child's Disabilities: Severe brain damage; visual and hearing impairment (02/14/86 to 09/87)
Affiliations: New England SERVE -- Executive Committee; Compassionate Friends -- Executive Board; PRO of Rhode Island -- Co-founder; Rhode Island Children's Hospital -- Parent Advisory Board
Care Facility: Rhode Island Group Health Association
Skills and Interests: Ethical issues; private-duty nursing (in-home) for children with technology dependence; parent/professional collaboration; insurance rights
Experience: Testified before the Rhode Island Maternal and Child Health Commission on needs of children with technology dependence; paticipated in the New England SERVE task force on standards and indicators for quality health care; starting or maintaining parent/family support groups; public speaking; promoting legislation
Related Employment: Parent consultant, Rhode Island Department of Health

SOUTH CAROLINA

Carol S. Harley
4833 Reamer Avenue
Columbia, SC 29206
803 253-6154
803 782-1557

Child's Disabilities: Autism; profound mental retardation; degenerative brain disorder; epilepsy
Affiliations: ARC; Society for Autistic Children; Epilepsy Association; PRO; Advocates for Children; Mental Health Association; Association for Children with Birth Defects
Skills and Interests: Information and referral services; parent training
Experience: Public speaking; conducting training sessions for health care providers or teachers; promoting legislation; starting or maintaining

parent/family support groups
Related Employment: Program Administrator, Quality Assurance Division, State Health and Human Services Finance Commission

Nancy S. Ott
503 Pitt Street
Mt. Pleasant, SC 29464
803 883-3586 (9 a.m. to 2 p.m.)
803 881-2036

Child's Disabilities: Lamellar ichthyosis (02/18/81)**Affiliations:** Foundation for Ichthyosis and Related Skin Types (formerly National Ichthyosis Foundation); Carolina Children's Charity; HED Foundation
Care Facility: Roper Hospital -- Charleston, SC
Skills and Interests: Coordination of multiple health care givers; coordination of parent support network; research pertaining to skin
Experience: Public speaking; starting or maintaining parent/family support groups

Bonnie Schmid
3A Rhodes Avenue
Shaw AFB, SC 29152

Child's Disabilities: Ollier disease (multiple enchondromatoses) (03/09/85)
Affiliations: Ollier Disease Self-Help Group -- Beaconsfield, Bucks, England
Care Facility: Private physician
Experience: Starting or maintaining parent/family support groups

SOUTH DAKOTA

Kent S. Alberty
2009 South Lyndale Avenue
Sioux Falls, SD 57105
605 339-1325
605 334-9762

Child's Disabilities: Cerebral palsy; seizures; gatrostomy tube; port-a-cath (08/25/80)
Affiliations: South Dakota Parent to Parent Inc. -- President; ARC
Care Facility: Central Plains Clinic and Sioux Valley Hospital -- Sioux Falls, SD
Skills and Interests: Parent advocacy; respite care
Experience: South Dakota Health Services Advisory Council; starting or maintaining parent/family support groups; public speaking; training health care providers

Virginia Conlee
Box 220
Kadoka, SD 57543
605 837-2211

Child's Disabilities: Mental and physical handicaps; severe hearing loss; failure to thrive; now uses cataract lenses (12/02/75)
Affiliations: Parent Connection
Care Facility: Rapid City Regional Hospital -- Rapid City, SD
Skills and Interests: Financing early intervention
Experience: Participated in comprehensive study of personnel development for TASH; Mountain Plain Regional Resource Committee (MPRRC) for the Early Childhood Interagency Coordinating Committee; State Advisory Council for Special Education; public speaking; promoting legislation

Dawn Kellogg
1714 38th Street
Rapid City, SD 57702
605 341-1955

Child's Disabilities: Static encephalopathy; microcephaly; severe developmental delay (06/07/81)
Affiliations: Parent Connection; Positive Parent Network; ARC -- Secretary; ACCH; Parent to Parent
Care Facility: Rapid City Regional Hospital -- Rapid City, SD
Skills and Interests: Expanding parent-to-parent outreach throughout state
Experience: State Department of Special Education, Interagency Council for developing and implementing guidelines for P.L. 99-457 -- Parent Representative; public speaking; leading training for health care providers; starting or maintaining parent/family support groups; state Special Education Administrative Rules Revision Committee -- Parent Representative
Related Employment: R.N. (Labor and delivery)

Ellen M. Schwenk
Route 1 Box 8A
Brookings, SD 57006

Child's Disabilities: Marshall-Smith syndrome with accelerated bone age; multiple anomalies;

gastrostomy; tracheostomy (05/18/82)
Care Facility: Crippled Children's Hospital and School and Sioux Valley Hospital -- Sioux Falls, SD
Experience: ICC -- former Parent Representative; Easter Seals -- former Respite Care Coordinator; public speaking; training parents and health care providers; elementary school principle and teacher

TENNESSEE

Pamela Cardoso
514 Crosswood Court
Nashville, TN 37214
615 885-6164

Child's Disabilities: Blindness; repaired cleft palate; growth hormone deficiency
Affiliations: National Association for Parents of the Visually Impaired (NAPVI) -- Co-editor, state newsletter, Tennessee Affiliate; Middle Tennessee Association for Persons with Severe Handicaps; Association for Retarded Citizens (Davidson County) -- Vice President; Middle Tennessee Association for Persons with Severe Handicaps
Care Facility: Vanderbilt University Medical Center -- Nashville, TN
Skills and Interests: Advocacy for early intervention, especially as related to P.L. 99-457; education for parent/professional collaboration
Experience: Public speaking; promoting legislation; maintaining parent/family support groups

Nancy Dean
12312 River Oaks Point
Knoxville, TN 37922
615 675-2740

Child's Disabilities: Blindness; cerebral palsy; severe mental retardation
Affiliations: Knox County Association of Retarded Citizens -- Board of Directors
Care Facility: East Tennessee Children's Rehabilitation Center -- Knoxville, TN
Skills and Interests: Parent-to-parent support; developed Mother's Day Out Program; developing sibling groups
Experience: Leading training for health providers/teachers; starting or maintaining parent/family support groups

Ann K. Farr
801A Teaberry Lane
Knoxville, TN 37919
615 691-2418

Child's Disabilities: Spina bifida; multiple chronic complications (04/19/81)
Affiliations: East Tennessee Spina Bifida Association -- Treasurer; POSTOP (Parents Offering Support To Other Parents) -- Co-founder and Treasurer; PARENTS (Parent Association for the Right to Educate Non-traditional Students) -- Founder and President; ACCH Parent Network; Learning Disability Association of East Tennessee -- Vice President; ACCH -- President Elect, East Tennessee Chapter
Care Facility: East Tennessee Children's Hospital -- Knoxville, TN
Skills and Interests: Improving education; early intervention; parent/professional training
Experience: Serving as member of the State Department of MHMR Planning Committee, Region II; working with the state health department as Parent Counselor in their Crippled Children's Services Clinics; working with hospital social workers to make referrals; public speaking; conducting training sessions for health care providers or teachers; promoting legislation; starting or maintaining parent/family support groups

Mary and Jim Goldsack
415 Wrather Place
Murfreesboro, TN 37130
615 898-2437 (Mary)
615 893-1449 (Jim)
615 893-2976

Child's Disabilities: Rhabdomyosarcoma; attention deficit disorder (02/17/79)
Affiliations: Parents of Special Children; ACCH; Parents of Learning Disabled; Vanderbilt University -- Chronic Illness Project Steering Committee, Parent Relation Committee, and Community & Education Service Committee
Care Facility: Vanderbilt University Hospital -- Nashville, TN
Skills and Interests: Hospital visitation policies; early intervention
Experience: Public speaking; starting or maintaining parent/family support groups; serving on local committee to plan a Ronald McDonald House; public speaking; training health care

providers; promoting legislation; 92-142 PTO trained
Related Employment: Nursing Instructor, Middle Tennessee State University

Linda Lemons
3260 Baskin
Memphis, TN 38127
901 353-9481

Child's Disabilities: Head injuries; head trauma; semi-comatose (01/18/81)
Affiliations: Project Sunshine (Parent support and volunteer respite care) -- Founder, Director, and Parent Coordinator
Care Facility: Lebonheur Children's Hospital -- Memphis, TN
Skills and Interests: Working on respite care
Experience: Public speaking; training health care providers/teachers; starting or maintaining parent/family support groups

TEXAS

Rosemary Alexander
3904 Galacia
Austin, TX 78759
512 346-0067

Child's Disabilities: Mental retardation; seizure disorder; cerebral palsy (04/28/82)
Affiliations: Infant Parent Training Program; Project 0-3; Children's Hospital of Austin; Austin Coalition of Parent Support Groups
Care Facility: Brackenridge Hospital -- Austin, TX
Skills and Interests: Writer in area of communication between families and experts; training for professionals; recreation
Experience: Working as a paid consultant to a Zero to 3 program for handicapped children; public speaking; conducting training sessions for health care providers or teachers; starting or maintaining parent/family support groups; organizing recreational activities for special families
Related Employment: Writer; Consultant for families and programs for handicapped, Project Zero to 3; Outreach at Children's Hospital of Austin

Sandra Bennett
109 Illa Street
Elgin, TX 78621
512 285-5287

Child's Disabilities: Chromosome syndrome; partial Trisomy 9 with a translocation on 20th chromosome (09/11/90)
Affiliations: Pride -- Early intervention services; Pilot Parents
Care Facility: Brackenridge Children's Hospital -- Austin, TX
Languages other than English: Spanish

Kay Biescar
Williams Syndrome Association
16211 North Greenfield Drive
Klein (Spring), TX 77379
713 376-7072
713 376-1626

Child's Disabilities: Williams syndrome (09/16/81)
Affiliations: Williams Syndrome Association -- Administrative Assistant and past Regional Director; Project "Keep Pace" Advisory Board (0-3 early intervention); TEXGENE (Texas Genetic Network); P.A.T.H.
Care Facility: Texas Children's Hospital -- Houston, TX
Skills and Interests: Early intervention
Experience: Serving as liaison for Williams Syndrome Clinic at Texas Children's Hospital; starting or maintaining parent/family support groups; public speaking; training parents and teachers
Related Employment: Administrative Assistant, Williams Syndrome Association

Catherine Blevins
15602 Laona Cove
Austin, TX 78717
512 255-7628

Child's Disabilities: Werdnig-Hoffmann disease
Affiliations: Families of Spinal Muscular Atrophy of Louisiana, Inc. -- Co-founder; The Education and Support Program of Children's Hospital (New Orleans) -- Co-founder
Care Facility: Texas Scottish Rite Hospital for Crippled Children -- Dallas, TX
Skills and Interests: Developing systems for

parent/professional collaboration; information and referral services
Experience: Co-founder of a "Supergroup," networking parents and professionals involved in support groups related to child health care; public speaking; starting or maintaining parent/family support groups
Languages other than English: Spanish

Maria E. Cardona
4928 Mission Avenue
Dallas, TX 75206
214 904-1175
214 828-0137

Child's Disabilities: Autism (09/13/81)
Affiliations: P.A.T.H. Project -- Volunteer; Autism Society of America -- Board Member, Dallas Area Chapter; ARC
Care Facility: Private physician -- Dallas, TX
Skills and Interests: Respite care; bilingual services
Experience: Helping to organize workshop toprovide information in Spanish to parents of children with disabilities; training parents
Related Employment: Teacher/Assistant in a deaf/blind multi-handicapped class
Languages other than English: Spanish; Sign language

Debi S. Daughn
1405 Mimosa Pass
Cedar Park, TX 78613
454-6861
331-7857

Child's Disabilities: Leukemia (ALL) (09/23/80 to 05/20/90)
Affiliations: Candlelighters Childhood Cancer Foudnation -- Newsletter Editor
Care Facility: Brackenridge Cildren's Hospital -- Austin, TX
Skills and Interests: Camps for brothers and sisters; support groups
Experience: AACCCF -- Parent Advisory Group; starting or maintaining parent/fmaily support groups; public speaking; training parents; promoting legislation
Related Employment: Surgical assistant
Languages other than English: Spanish

Christy Dees
15900 Fennimcrelove
Austin, TX 78717
512 323-3239
512 255-1309

Children's Disabilities: Hearing impairment; learning disability (07/03/80); Down syndrome; ADHA (11/12/85)
Affiliations: Pilot Parents -- Advisory Board; PRIDE Program Parent Support Group
Care Facility: Private physician; Brackenridge Hospital -- Austin, TX; Early Childhood Intervention through Travis State School PRIDE Program
Skills and Interests: Parent involvement in early intervention, especially at the policymaking level
Experience: Employed by the state Early Childhood Intervention Program to monitor local programs for compliance to P.L. 99-457, to develop IFSP policies for Texas, and to provide technical assistance to programs needing family focus skills; starting or maintaining parent/family support groups; public speaking

Robert L. Dunning
5309 Farragut Drive
Arlington, TX 76018
214 754-1410
817 468-4520

Child's Disabilities: Mental retardation (03/19/83)
Affiliations: P.A.T.H. -- Parent Assistant Specialist; SAFE-Arlington -- President; Our Special Children
Care Facility: Private physician -- Arlington, TX
Skills and Interests: Integration; inclusion; transition planning
Experience: School District Special Education Advisory Committee; starting or maintaining parent/family support groups; public speaking; training parents; promoting legislation

Janice Foreman
785 Brandywine
Beaumont, TX 77706
409 866-4726

Child's Disabilities: Down syndrome; scoliosis; allergies; seizures (09/27/71 to 12/01/87)
Affiliations: ARC-TX; ACLD-TX; Mental Health Association; *Partnerships for Assisting Texans with Handicaps (PATH)

Care Facility: Shriner's Hospital for Crippled Children -- Houston, TX; UTMB/John Sealy Hospital -- Galveston, TX
Skills and Interests: Public school services; parent training; parent-to-parent support; community residential programs
Experience: Starting or maintaining parent/family support groups; public speaking; training parents, health care providers, or teachers; promoting legislation
Related Employment: Co-director, *PATH

Valerie R. Goodwin
6025 Edgewater Drive
Corpus Christi, TX 78412
512 991-8923

Child's Disabilities: Undiagnosed, possible damage from Pertussis vaccine (03/30/81 to 04/89)
Care Facility: Driscoll Foundation Children's Hospital, Human Development Center, and Ada Wilson Hospital -- Corpus Christi, TX; HeritageManor Care Center -- Hondo, TX
Skills and Interests: Advocacy; networking; child life services in hospitals; environments for healing; family resource library services
Experience: Public speaking; conducting training sessions for health care providers; starting or maintaining parent/family support groups; serving on regional follow-up committee for State Debate on Health Care Conference; co-chaired Junior League project to fund and start a Child Life Department at the Driscoll Foundation Children's Hospital and worked with Junior League to fund and start a Parents' Resource Library at the Ada Wilson Hospital for the Handicapped; testified before the Task Force on Technology Dependent Children -- Washington, DC

Jewetta and Vernon Himes
P.O. Box 151034
Irving, TX 75015-1034
214 642-8514

Child's Disabilities: Head injury; mid-brain damage leading to semi-comatose condition (04/14/71)
Affiliations: Texas Head Injury Foundation, North Central Chapter
Care Facility: Parkland Memorial Hospital -- Dallas, TX; Dallas/Fort Worth Medical Center -- Grand Prairie, TX; and Hillcrest Baptist Medical Center -- Waco, TX
Skills and Interests: Networking with families of children with head injuries; forming a network for parents of children with special needs who have no insurance coverage

Steve and Dorothy Hull
ST 97 Lake Cherokee
Henderson, TX 75652
214 643-0936

Child's Disabilities: Down syndrome (04/23/82)
Affiliations: H.A.N.D.S. (Helping Adapt to Newborns with Developmental Delays) -- Vice President and past President; S.A.F.E. (Schools Are For Everyone) -- Parent Member; ARC-TX -- Parent Volunteer, Committee Representative, and Parent Support Representative; P.A.T.H.
Experience: T.P.P.I.N. (Texas Parent/Professional Information Network) workshop; workshops for Advocacy, Inc./Texas; ARC-TX -- Parent Legislative Advocate (testifying before committees); starting or maintaining parent/family support groups; training parents, health care providers, and teachers; promoting legislation

Lourdes Johnson
10400 Kasey Way
El Paso, TX 79927
915 858-4310
915 858-4310

Child's Disabilities: Hearing impairment; ADHD (05/22/85)
Affiliations: Texas Association of Parents and Educators of the Deaf -- President Elect; West Texas Association of Persons with Disabilities
Care Facility: Private physicians
Skills and Interests: Respite care; financing; early intervention; starting or maintaining parent/family support groups; public speaking; training parents; promoting legislation
Related Employment: Area Development Director
Languages other than English: Spanish; Sign language

Colette Lau
Facial Expressions
P.O. Box 262481
Houston, TX 77207-2481

Child's Disabilities: Craniofacial deformity (06/20/84)
Affiliations: Facial Expressions -- Founder
Care Facility: St. Joseph's Hospital -- Houston, TX
Skills and Interests: Providing parent-to-parent support; helping to educate community, both personally and professionally
Experience: Public speaking; starting or maintaining parent/family support groups

Rita and David Matthews
2615 Audford Drive
Austin, TX 78745
512 477-2511
512 440-0369

Child's Disabilities: Camptomelic dysplasia (10/04/84)
Affiliations: Special Education Booster Club
Care Facility: Children's Hospital of Austin
Skills and Interests: Financial assistance; play groups
Experience: Training health care providers
Related Employment: R.N., Seton Medical Center
Languages other than English: German

Jeanie Pemberton
1530 Evergreen
Lewisville, TX 75067
214 436-4255

Child's Disabilities: Autism; mental retardation (04/25/79)
Affiliations: Autism Society of America -- President, Dallas Chapter; SAFE (Schools Are For Everyone, Inc.); *Partnerships for Assisting Texans with Handicaps (PATH) -- Parent Specialist; ARC -- Dallas Chapter; Autism Society of America -- former Board Member, Texas Chapter
Care Facility: Pediatric Associates -- Lewisville, TX
Experience: Planning workshops and training programs; starting or maintaining parent/family support groups; public speaking; training parents and teachers; promoting legislation

Diana Buder Phillips
207 East Milton
Austin, TX 78704
512 478-9681 or 4618
512 445-0414

Child's Disabilities: Acute Lymphocytic Leukemia (09/08/82)
Affiliations: Austin Area Candlelighters -- Executive Director and former President, Board of Directors; Parent Place (parent library and retreat) -- Founding Member and Advisory Board Member; Children's Hospital Specialty Care Center -- Advisory Board Member
Care Facility: Brackenridge Children's Hospital and private physician -- Austin,TX
Skills and Interests: Long-term follow-up and side effects for childhood cancer survivors; education and support services for children with cancer and their brothers and sisters and parents
Experience: Developing childhood cancer awareness program; American Cancer Society -- Texas Division Parent Teaching Conference Planning Committee; starting or maintaining parent/family support groups; public speaking; training parents, health care providers, and
Related Employment: Community Relations & Education Coordinator, Shivers Radiation Center and Executive Director, Austin Area Candlelighters

Charlotte Provencher
TEXAMI CAN
208 Carswell
Waco, TX 76705
817 799-5019

Child's Disabilities: Mental illness (03/14/75)
Affiliations: Waco Alliance for the Mentally Ill -- President; Children and Adolescents Network of Texas Alliance -- State Coordinator
Care Facility: Local Mental Health Agency
Skills and Interests: Funding for youth Mental Health services; advocacy for community-based Mental Health services for youth
Experience: Starting or maintaining parent/family support groups; public speaking; training parents, health care providers, or teachers; promoting legislation
Related Employment: Coordinator for a federal grant for Mental Health services for youth and families, Partners Resource Network

Rashid and Martha Qureshi
7802 Swindon Lane
Austin, TX 78745-6826
512 441-7602

Child's Disabilities: Cerebral palsy with seizure disorder (07/06/86)
Affiliations: PASS (Parent Association of Seizure Support) -- Martha -- Treasurer; Cerebral Palsy Support Group; Pilot Parent
Care Facility: Children's Hospital at Brackenridge, Travis Children's Clinic, and Austin Neurological Clinic -- Austin, TX
Skills and Interests: Respite care
Experience: Texas ARC -- Parent Advisory Committee; starting or maintaining parent/family support groups; training parents, health care providers, and teachers; promoting legislation
Languages other than English: Martha -- Spanish; Rashid -- Urdu (Pakistani)

Lea Ramsour
35 North 8th Street
Beaumont, TX 77702
409 832-6480

Child's Disabilities: Closed head injury (11/21/69)
Affiliations: Texas Head Injury Association; South East Texas Head Injury Association -- Executive Committee; *Partnerships for Assisting Texans with Handicaps (PATH) -- Parent Assistant Specialist and Program Coordinator; Parent to Parent Project; Traumatic Brain Injry Research Program -- Standing committees
Care Facility: The Institute for Rehabilitation and Research -- Houston, TX
Skills and Interests: Community based and inclusive services; funding for rehabilitation
Experience: Starting or maintaining parent/family support groups; public speaking; training parents, health care providers, or teachers; promoting legislation

Brenda Rapp
1117 Coker Drive
Flower Mound, TX 75028
214 539-7050

Child's Disabilities: Cystic fibrosis
Affiliations: Cystic Fibrosis Foundation -- Board Member; Public Policy Committee -- Parent Advisor; Cystic Fibrosis Information Time (information for patients and families) -- past Chairperson; Public Speakers Bureau -- Chairperson
Care Facility: Children's Medical Center -- Dallas, TX
Skills and Interests: Parent and family advocacy; education on cystic fibrosis for patients and families; insurance concerns at state level; designing and implementing an annual educational and emotional support day for patients and families
Experience: Cystic Fibrosis Foundation activities include: Patient Services Committee Chairperson, Public Policy Committee Advisor, Cystic Fibrosis Information Time Committee, and Cystic Fibrosis Speakers' Bureau; public speaking; leading training for health providers/teachers; promoting legislation; telephone support for newly diagnosed families

Anne Russell
3629 Norcross Lane
Dallas, TX 75229
214 956-7532

Child's Disabilities: Autism; developmental delay (04/14/84)
Affiliations: P.A.T.H. -- Parent Assistant Volunteer; ARC-Dallas -- Chairwoman, Education Committee; Autism Society of America -- Board Member, Dallas and Texas Chapters
Care Facility: Private physicians
Skills and Interests: Educational programs; transition; housing options for individuals with disabilities
Experience: Public speaking; promoting legislation

Candy Sheehan
759 Pelican Lane
Coppell, TX 75019
214 462-7830

Child's Disabilities: Hydrocephalus; cerebral palsy; seizure disorder (07/24/85)
Affiliations: P.A.T.H. -- Project Assistant Specialist; Hydrocephalus Association of North Texas (HANT) -- Vice president; Parent Organization for Easter Seal Society -- Special Events Chairwoman; Dallas Epilepsy Association -- Volunteer, Kids on the Block

Care Facility: Humana Hospital Medical City of Dallas -- Dallas, TX
Skills and Interests: Early intervention; early childhood and elementary school education; advocacy; barrier-free facilities
Experience: Special Education Parent Advisory Committee; Partners in Policymaking, DD Council in Texas P.A.T.H.; starting or maintaining parent/family support groups; public speaking; training parents
Related Employment: Volunteer

Vicki Sommers
306 San Carlos
Irving, TX 75062
214 791-1189

Children's Disabilities: Down syndrome (08/24/82); Developmental delay (10/11/84)
Affiliations: Parent Support Group of the Helping Hand Development Center -- President;Statewide Network for Early Childhood Intervention -- Chairperson; Down Syndrome Guild of Dallas -- Board Member, Legislation; Project 0-3 -- Parent Representative
Care Facility: Medical & Surgical Clinic -- Irving, TX
Skills and Interests: Advocating for better special education
Experience: Serving on the Ad Hoc Steering Committee for Early Childhood Intervention in Texas; serving as parent consultant to the state health department for early intervention programs; starting or maintaining parent/family support groups; public speaking; training parents; promoting legislation

Cathy Stark
211 Inwood Drive
Palestine, TX 75801

Child's Disabilities: Dyslexia (04/29/71)
Affiliations: ACLD; *Partnerships for Assisting Texans with Handicaps (PATH); LDA, Inc.; National Dyslexia Referral Center; TACLD -- President; Orton Dyslexia Society
Skills and Interests: Intervention; parent advocacy
Experience: Working with *PATH in developing and continuing the Transitional Training Program; starting or maintaining parent/family support groups; public speaking; training parents, health care providers, or teachers; promoting legislation
Related Employment: Advocate, *PATH and TACLD

Francine Templeton
827 Shady Point, #61
Arlington, TX 76013
817 261-7061

Child's Disabilities: Cleft palate; learning disability; epilepsy; behavior disorder (04/08/80)
Affiliations: Partnerships Assisting Texans with Handicaps -- Area Development Director/Northeast Texas; Schools Are for Everyone -- Arlington, Texas Chapter; Children's Medical Center -- Facial Anomalies Support Group; Facial Expressions/Houston
Care Facility: Cook-Fort Worth Hospital; Children's Medical Center -- Dallas, TX
Skills and Interests: Insurance legislation; health care financing; education issues, especially integration and rural education
Experience: North Texas Computer Access Center -- Steering Committee; starting or maintaining parent/family support groups; public speaking; training parents, health care providers, and teachers
Related Employment: P.A.T.H. Project -- Parent Training and Information Network for Texas

Virginia M. Tipton
5608 Fence Row
Austin, TX 78744
512 462-7207
512 447-6438

Child's Disabilities: Remission ALL (10/31/78)
Affiliations: Austin Area Candlelighters
Care Facility: Brackenridge Austin and Brackenridge Children's Hospital -- Austin, TX
Skills and Interests: Spiritual support
Experience: Starting or maintaining parent/family support groups; public speaking

Pam Tomsky
RR 3 Box 445
Eastland, TX 76448-9803
817 629-1239

Child's Facilities: Down syndrome (05/20/83)
Affiliations: "Special Needs" Parent Support

Group -- Chairperson; Down Syndrome Guild of Dallas; ARC -- past Board Member
Care Facility: Children's Medical Center -- Dallas, TX
Experience: P.A.T.H. -- Parent Assistant Specialist for Dallas area; starting or maintaining parent/family support groups; training parents

Elaine Viola
1504 B West 39th
Austin, TX 78703

Child's Disabilities: Rhizomelic chondrodysplasia punctata (09/05/86)
Affiliations: Austin Center for Attitudinal Healing -- Group Facilitator; Pilot Parent -- Case Manager; Coalition for Parent Support Groups
Care Facility: Children's Hospital -- Austin, TX
Skills and Interests: Creating a broader and more in-depth system of family support
Experience: ECI Interagency Council -- Grant Review Team Member; starting or maintaining parent/family support groups; training parents, health care providers, and teachers; public speaking; promoting legislation
Related Employment: Pilot Parent Case Manager, ARC-Austin

Marilou Wright
1603 Garfield
Wichita Falls, TX 76309
817 723-2613

Child's Disabilities: Learning disabilities (06/13/63)
Affiliations: A.C.L.D. -- Vocational Chairman, Texas A.C.L.D.; P.A.T.H. -- Area Development Director; Advocacy, Inc. -- Board of Directors
Care Facility: Wichita Falls -- Arlington, TX
Skills and Interests: Transition; respite care; vocational issues
Experience: Promoting legislation; starting or maintaining parent/family support groups; public speaking; training parents, health care providers, and teachers
Related Employment: Area Development Director, P.A.T.H. Project, Partners, Resource Network, Inc.

UTAH

Trisha Beck
1783 East 9880, S.
Sandy, UT 84092
801 572-2325

Child's Disabilities: Down syndrome
Affiliations: Utah Comprehensive Insurance Pool for Uninsurables -- Consumer Board Member; Parent to Parent of Utah -- Co-founder and Volunteer
Care Facility: Primary Children's Medical Center -- Salt Lake City, UT
Skills and Interests: Public and professional education regarding the needs of children with handicapping conditions and their families; legislative issues
Experience: Public speaking; conducting training sessions for health care providers and students in special education; worked to pass four bills in the last four years for families with members with special needs (most recent legislation is Insurance Risk Pool); national presentations on mainstreaming children with disabilities into neighborhood schools

Susie Perrett
575 South Hazel Drive
P.O. Box 820
Salem, UT 84653

Child's Disabilities: Brain injury due to automobile accident (11/01/82)
Affiliations: Division of Early Childhood, CEC -- Board Member
Care Facility: Primary Children's Medical Center -- Salt Lake City, UT
Skills and Interests: Preschool special education; family focus; parent/professional partnerships
Experience: State Interagency Coordinating Council; early intervention
Related Employment: Preschool Special Educator; Director, Kids Who Count Early Intervention Service

Melynda Richards
6768 Berula Circle
West Jordan, UT 84084
801 965-8046

Child's Disabilities: Short bowel syndrome; hearing impairment; prematurity
Affiliations: Parent Infant Program; Make a

Wish Foundation; Legislative Coalition for People with Disabilities
Care Facility: Primary Children's Hospital, University of Utah -- Salt Lake City, UT
Skills and Interests: Advocating for parents' rights at the hospital and other care facilities; research and advancements in home TPN (total parenteral nutrition)
Experience: Public speaking; conducting training sessions for health care providers or teachers; teaching medical students to deal with parents as a parent; promoting legislation; starting or maintaining parent/family support groups
Related Employment: Nursing student

Grace Adams Sisco
7893 Titian Way
Salt Lake City, UT 84121

Child's Disabilities: Osteogenesis imperfecta (severe) with complications; oxygen dependence for two years
Affiliations: Osteogenesis Imperfecta (OI) Foundation; Easter Seal Society of Utah
Care Facility: National Institutes of Health -- Bethesda, MD; University of Utah Medical Center, Pulmonary and Genetics (outpatient) and Primary Children's Medical Center (x-rays and physical therapy) -- Salt Lake City, UT
Skills and Interests: Public education to promote understanding of OI and importance of early intervention programs; financing and legislation; respite care; developing OI resources directory for pediatricians and hospital newborn nurseries
Experience: Public speaking; promoting legislation; starting or maintaining parent/family support groups; previously employed in Health Department Productivity and Finance Office

VERMONT

Nancy Abernathey
RR 2 Box 962
Underhill, VT 05489
802 899-2425

Child's Disabilities: Kniest syndrome with profound hearing loss
Affiliations: Vermont State Health Department; Handicapped Children's Service Advisory Council; March of Dimes Health Professional Advisory Committee; New England SERVE Executive Committee
Care Facility: Medical Center Hospital of Vermont -- Burlington, VT
Skills and Interests: Parent/professional relationships; parent-to-parent support; pre- and inservice training for health care professionals
Experience: Public speaking; starting or maintaining NICU parent support groups; working with *Vermont Information and Training Network
Related Employment: Program Coordinator, Parent to Parent of Vermont
Languages other than English: Sign language

Debra R. Asselin
Welch Road
Topsham, VT 05076
802 439-5282

Child's Disabilities: Prematurity; bronchopulmonary dysplasia
Affiliations: Parents of Premies
Care Facility: Massachusetts General Hospital -- Boston, MA
Skills and Interests: Parent-to-parent support groups; training and support for families
Experience: Public speaking; leading training for health providers/teachers; starting or maintaining parent/family support groups; working with state health departments

Anne Bakeman
3 Bedford Green
South Burlington, VT 05403
802 658-3374

Child's Disabilities: Autism (1967)
Affiliations: Champlain ARC -- President; *Vermont Information and Training Network Project; Autism Society of Vermont
Skills and Interests: Transition; supported employment
Experience: Serving on the Vermont Coalition for Disability Rights Legislative Committee; starting or maintaining parent/family support groups; public speaking; training parents, health care providers, or teachers; promoting legislation; coordinating and running conferences

Tanya Baker-McCue
20 Hullcrest Road
Shelburne, VT 05482
658-1914
985-2401

Child's Disabilities: Cystic fibrosis (12/06/83)
Affiliations: Parent-to-Parent of Vermont -- Board President; Brookes Baker Support Fund -- Founder; New England Genetics -- Advisory Member
Care Facility: Medical Center Hospital of Vermont and Cystic Fibrosis & Pediatric Pulmonary Center -- Burlington, VT
Skills and Interests: Respite care; financing; early intervention
Experience: Local CARC activities; starting or maintaining parent/family support groups; public speaking; training parents, health care providers, or teachers; promoting legislation
Related Employment: Director of Services Coordination, Mental Retardation Unit, Houward Mental Health -- Burlington, VT
Languages other than English: Sign language

Rochelle S. Boomhower
RD 2, 10 Mt. View Heights
Jericho, VT 05465
802 899-2370

Child's Disabilities: Chronic encopresis; emotional disability
Affiliations: Family Education Association -- President and Facilitator; CASSP (Parent Support Group) -- Facilitator; *Vermont Information and Training Network -- Volunteer Parent Support
Care Facility: University Health Center and Haward Mental Health -- Burlington, VT
Skills and Interests: Interested in groups for chronic encopretic children, adolescents, and professionals who work with these families to develop available information about the illness and cure and effects on families
Experience: Vermont delegate for Families as Allies to encourage collaboration between professionals and parents of severely emotionally disturbed children; public speaking; conducting training sessions for health care providers or teachers; starting or maintaining parent/family support groups
Related Employment: Social Worker; Parent Training Specialist, *Vermont Information and Training Network

John and Lynn Brennan
2 Lakewood Court
Colchester, VT 05446
802 658-3921

Child's Disabilities: Moebius syndrome (12/84)
Affiliations: Parent to Parent of Vermont -- Board of Directors; Support Can be Fun; Vermont Association for Retard Citizens (VARC)
Care Facility: Medical Center Hospital of Vermont -- Burlington, VT
Skills and Interests: Respite care; early intervention
Experience: Early Intervention Planning Team (working on implementing P.L. 99-457, Part H) -- Chairperson; starting or maintaining parent/family support groups; public speaking; training health care providers; promoting legislation
Related Employment: Vermont Family LINCS Chairperson

Nancy DiVenere
1 Main Street, #69 Champlain Mill
Winooski, VT 05404
802 655-5290
802 878-4549

Child's Disabilities: Mild cerebral palsy; learning disability (03/76)
Affiliations: Parent-to-Parent of Vermont; Division for Children with Special Health Needs; Medical Education Project (collaborative project between Parent-to-Parent of Vermont and University of Vermont College of Medicine to enhance education of medical students); University of Vermont -- Coordinator and Supervisor of Practicum Seminar; Family-Centered Institute Project (to infuse family-centered principles into curriculum development at colleges and universities) -- Co-facilitator
Care Facility: Medical Center Hospital of Vermont -- Burlington, VT
Skills and Interests: Parent-to-parent support; parent/professional collaboration
Experience: Developing and implementing outreach programs for health care providers on the value and importance of support; implementing Medical Education Project by attending lectures and facilitating home visits for medical students and residents in an effort to increase awareness of issues concerning children with special needs and their families

Related Employment: Director, Parent to Parent of Vermont

Charlie & Suzi Hillman
120 Lakewood Parkway
Burlington, VT 05401
802 658-6082

Child's Disabilities: Wolf syndrome (4P-) (10/30/83)
Affiliations: Parent-to-Parent of Vermont -- Vice President; LINCS of Chittenden County; Support Can be Fun; I Team -- Parent Advisory Council Member
Care Facility: Private physician
Skills and Interests: Early intervention issues -- lack of funding and services for birth to three
Experience: Public speaking; promoting legislation

John and Pam Jackson
RR 2 Box 2672
Plains Road
Pittsford, VT 05763
802 483-2072

Child's Disabilities: Angleman syndrome (05/21/84)
Affiliations: Common Bond
Care Facility: Rutland Regional Medical Center -- Rutland, VT
Skills and interests: Improving health care and education for children
Experience: Starting or maintaining parent/family support groups
Related Employment: X-ray Technologists, Rutland Regional Medical Center

Margaret Knapp
RR 1 Box 1420
Northfield, VT 05663
802 485-7047

Child's Disabilities: Spina bifida (11/26/81)
Affiliations: Parent-to-Parent of Vermont -- Regional Parent Coordinator; Spina Bifida Association of Vermont
Care Facility: Medical Center Hospital of Vermont -- Burlington, VT
Skills and Interests: Respite care; financing; early intervention; recreation
Experience: LINCS; Handicapped Children's Service Advisory Board; starting or maintaining parent/family support groups; public speaking; training parents
Related Employment: Regional Parent Coordinator, Parent-to-Parent of Vermont

Elizabeth Milizia
77 Bayberry Lane
South Burlington, VT 05403
802 655-4014
802 658-7419

Child's Disabilities: Down syndrome; has had corrective cardiac surgery
Affiliations: Champlain Association for Retarded Citizens; Parent to Parent of Vermont; Vermont Parent/Professional Partnership Workgroup; Vermont Developmental Disabilities Council; Northeast Regional Resource Center Advisory Council
Care Facility: Medical Center Hospital of Vermont
Skills and Interests: Parent support networks; parent/professional relationships; total inclusion of people with disabilities in all aspects of community life; due process at the preschool level (least restrictive environment); public speaking
Experience: Overseeing legislative network of families and others; providing one-to-one systems advocacy to individuals with disabilities and their families; legislative lobbying; implementing various trainings related to quality of life issues for people with disabilities and their families in collaboration with the Vermont Department of Mental Health/Mental Retardation and the University of Vermont
Related Employment: Elizabeth -- Coordinator, Vermont Association for Retarded Citizens; Steve -- Supported Employment Job Developer (developing jobs in community for individuals with severe disabilities), Howard Community Services

Maureen Mitchell
RD 1, Box 296
Pownal, VT 05261
802 823-5256

Child's Disabilities: Cerebral palsy; blindness; mental retardation (01/30/76)
Affiliations: Parent-to-Parent of Vermont -- Regional Parent Coordinator; LINCS (Local Interagency Network for Community Supports) -- Co-chair; New England SERVE -- Health Care Financing Committee
Care Facility: Community Health Plan -- Hoosick Falls, NY; Albany Medical Center --

Albany, NY; Southwest Vermont Medical Center -- Bennington, VT
Skills and Interests: Health care financing; IEP's; legislation
Experience: ICC for Bennington County, VT; starting or maintaining parent/family support groups; public speaking; training health care providers, parents, and teachers; promoting legislation
Related Employment: Regional Parent Coordinator, Bennington/Rutland Regions, Parent-to-Parent of Vermont

Paul F. and Susan L. Rump
P.O. Box 174
Thetford Center, VT 05075
802 785-4029 (evenings)

Child's disabilities: Cobalamin G (inborn error of Vitamin B12 metabolism); resultant seizure disorder (aftermath of hypsarrhythmia -- myoclonic spasms) (11/17/84)
Affiliations: Upper Valley Support Group -- New Hampshire/Vermont; Association for Neuro-Metabolic Disorders; Research Trust for Metabolic Diseases in Children; Upper Valley Association for Handicapped Citizens
Care Facility: The Massachusetts General Hospital -- Boston, MA
Skills and Interests: Networking with other parents of children with similar disorders; encouraging the state to expand its neonatal screening services; attending local parent education meetings held; writing occasional articles; inclusionary education
Experience: *Vermont Information and Training Network (telephone network); respite training workshop participant; UVSG; educational presentations to physicians' groups; participant in New England Project Serve to facilitate implementation of P.L. 99-457
Related Employment: Susan -- Teacher, participates in integrating students with intensive learning needs; Paul -- physician's assistant

Pam Spinney
P.O. Box 2307
West Brattleboro, VT 05301
802 257-5808

Children's Disabilities: Down syndrome; cardiac defects (09/10/81 and 09/14/83)
Affiliations: *Vermont Information and Training Network; The Association for Special Kids (TASK); ARC of Vermont; Northern New England Down Syndrome Congress
Care Facility: Children's Hospital -- Boston, MA
Skills and Interests: Parents as participants in local, state, and federal policy development for programs serving all families
Experience: Serving as member of the Vermont Interagency Coordinating Council for P.L. 99-457; working with the state education department -- Parent Coordinator for P.L. 99-457; starting or maintaining parent/family support networks; training parents; public speaking
Related Employment: Department of Education -- Montpelier, VT

Susan Yuan
499 C Waterman
University of Vermont
Burlington, VT 05405
802 656-1331
802 899-2883

Child's Disabilities: Thiamine responsive lactic acidosis (pyruvate dehydrogenase deficiency) (02/15/74)
Affiliations: TASH; New England TASH; CARC -- Vice President; Parent-to-Parent; Vermont Family Support Network; Vermont I-Team -- Family Resource Consultant
Care Facility: University Health Center -- Burlington, VT
Skills and Interests: Respite care; family support; integrated education
Experience: Vermont Special Education Advisory Council; Vermont Developmental Disabilities Council; Mental Retardation Advisory Board -- Family Support Subcommittee; Howard Mental Health Services -- Board Member; Chittenden County LINCS (ICC for 99-457); starting or maintaining parent/family support groups; public speaking; training parents and teachers; promoting legislation
Related Employment: Coordinator, Family Support Project, Center for Developmental Disabilities, UVM -- Burlington, VT

VIRGIN ISLANDS

Edith P. Johnson
Parent Power Support Group, Inc.
P.O. Box 2553
St. Thomas, U.S. Virgin Islands 00803
809 774-8276/775-6911
809 776-5179

Child's Disabilities: Dyslexia (11/06/78)
Affiliations: Parent Power Support Group, Inc. (support group for children with disabilities on the Islands of St. Thomas and St. John) -- Secretary
Skills and Interests: Respite care; health care financing
Experience: Starting or maintaining parent/family support groups

Dolorita Massiah
Our Parent Support Group, Inc.
P.O. Box 25744
Christiansted, St. Croix, U.S. Virgin Islands 00824
809 778-8733

Child's Disabilities: Autism (07/10/67)
Affiliations: Our Parent Support Group, Inc. -- President
Experience: Starting or maintaining parent/family support groups; public speaking

VIRGINIA

Lana Ambler
8651 Poplar Glen Court
Vienna, VA 22180
703 255-3899

Child's Disabilities: Apert syndrome (01/16/78)
Affiliations: Parents of the Physically Handicapped (Fairfax County, VA) -- Secretary; *Parent Education Advocacy Training Center; Special Olympics; International Craniofacial Foundation
Care Facility: Children's Hospital National Medical Center -- Washington, DC
Skills and Interests: Developing paid parent positions in clinics or hospitals
Experience: Training parents, health care providers, and teachers
Related Employment: Information Service Coordinator, National Information Center for Children and Youth with Handicaps

Sue Ferguson
505 East Columbia Street
Falls Church, VA 22046
703 237-9089

Child's Disabilities: Cerebral palsy; seizure disorder (04/20/83)
Care Facility: Georgetown University Hospital -- Washington, DC
Skills and Interests: Developing case management services for families; promoting legislation
Experience: Degrees and experience in special education

Cindy Lucas
6611 Brittewood Circle
Mechanicsville, VA 23111
804 730-1190

Children's Disabilities: Congenital heart defect (left transposition single ventricule) (06/13/85); Dyslexia (10/31/79)
Affiliations: Sharing Hearts; Parent-to-Parent -- Parent partner; MCV -- Volunteer Auxiliary
Care Facility: Medical College of Virginia (MCV) -- Richmond, VA
Skills and Interests: Broader testing for learning disabilities at earlier ages
Experience: Maintaining parent/family support groups

Eileen Ouellette
5369 Susquehanna Drive
Virginia Beach, VA 23462
804 499-1035

Child's Disabilities: Developmental delay (03/09/88)
Care Facility: Boone Clinic -- Little Creek Naval Base, Virginia Beach, VA
Experience: Child Development Center -- Parent Advisory Board; starting or maintaining parent/family support groups; public speaking

Vonna Privett
202 Manassas Drive
Manassas Park, VA 22111
703 369-5838

Child's Disabilities: Spina bifida; hydrocephalus (with 17 shunt VP revisions); hydromyelia (with 7LP revisions); hydronephrosis; Arnold-Chiari syndrome (12/14/83)

Affiliations: Spina Bifida Association/DC Chapter; Virginia ARC; P.I.E. Program 0 to 2 years (phone networking); Special Education Advisory Board -- Chairperson
Care Facility: Univeristy of Virginia Children's Medical Center and Kluge Children's Rehabilitation Center -- Charlottesville, VA
Skills and Interests: Certification of teachers and teachers' aides to teach children with special needs; orienting teachers to the children's conditions
Experience: Working with a parent advisory board; beginning a day care/respite program with the ARC; working with the Family Autonomy Project at University of Virginia Children's Medical Center; starting or maintaining parent/family support groups; public speaking; promoting legislation
Related Employment: Secretary for private practice physician

Jane Purdy
4615 Gramlee Circle
Fairfax, VA 22032
703 978-4111

Child's Disabilities: Cerebral palsy; learning disability; attention deficit disorder (07/11/80)
Affiliations: Northern Virginia ACLD; ARC; Committee for Exceptional Children
Care Facility: Children's Hospital National Medical Center -- Washington, DC
Skills and Interests: Public speaking and writing; parent-to-parent support; consulting with military families of children with special needs
Experience: Public speaking; leading training for health providers/teachers; starting or maintaining parent/family support groups; working with state health departments; author of a personal book, *He Will Never Remember* (child abuse)
Related Employment: R.N.; Special Needs Family Specialist, U.S. Coast Guard; principal author of guidelines for family use of respite care published by ACCH in 1989

Patty Smith
The National Parent Network on Disabilities
1600 Prince Street, Suite 115
Alexandria, VA 22514
703 684-6763

Child's Disabilities: Mild mental retardation; epilepsy (05/26/70)
Affiliations: ARC of the U.S.; ARC of Northern Virginia; TASH; United Cerebral Palsy of America; ACCH; American Council of Rural Special Educators; National Center for Clinical Infant Programs; National Association for the Mentally Ill; National Network of Parent Centers
Care Facility: University of Maryland Hospital -- Baltimore, MD
Experience: Set up statewide family support network and respite care services in Nebraska as a paid parent consultant at the Meyer Children's Rehabilitation Institute and the Greater Omaha ARC for Pilot Parents; on leave from position as Deputy Director of the National Information Center for Handicapped Children and Youth; served on numerous boards, advisory committees, and task forces; public speaking; conducting training sessions for health care providers, teachers, students, and parents; promoting legislation; starting or maintaining parent/family support groups; worked with the Nebraska Health Department
Related Employment: Executive Directory, The National Parent Network on Disabilities

Greg and Lori Weigle
451 Orchard Street
Vienna, VA 22180
703 281-1211

Children's Disabilities: Two children with Down syndrome (01/20/69 and 10/17/79); A third child with seizure disorder; failure to thrive (04/01/85)
Affiliations: Alliance of Genetic Support Groups; Parents of Children with Down Syndrome; National Down Syndrome Congress; National Center for Education in Maternal & Child Health
Care Facility: Children's Hospital National Medical Center and Georgetown University Hospital -- Washington, DC; Fairfax Hospital -- Fairfax, VA
Skills and Interests: Advocacy at the state and national level; assisting with foster care, adoptions, and parent outreach; professional education
Experience: Public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining parent/family support groups; working with state health departments

WASHINGTON

Barbara Bilyeu
2603 North Union Avenue
Tacoma, WA 98407
206 759-7933

Child's Disabilities: Sturge-Weber syndrome (07/70)**Skills and Interests:** Parent training in P.L. 94-142; least restrictive environment; normalization and transition
Experience: Federal Way Local Education Agency Parents Advisory Council -- past President; speaker on educational rights and responsibilities for parents of children with special needs; leading training for health providers/teachers; promoting legislation; starting or maintaining parent/family support groups; previously employed by *PAVE

Jo Butts
6316 South 12th
Tacoma, WA 98465
206 565-2266
206 893-2395

Child's Disabilities: Cerebral palsy; learning disability (03/08/66)
Affiliations: *Parents Advocating Vocational Education (PAVE) -- Assistant Director; TAPP (Technical Assistance for Parents Program) -- Technical Assistance Coordinator
Care Facility: Good Samaritan Children's Therapy Unit -- Puyallup, WA
Skills and Interests: Support for parents; leading training in P.L. 94-142
Experience: Public speaking; leading training for health providers/teachers; starting or maintaining parent/family support groups
Related Employment: Assistant Director, *PAVE

Vicki F. Draper
172 Draper Road
Rochester, WA 98579
206 273-5768

Children's Disabilities: Down syndrome (02/18/78); Mild cerebral palsy (05/11/79)
Affiliations: *Parents Advocating Vocational Education (PAVE) -- Community Liaison for South Thurston County/Lewis County; Rochester School District Parent Group; Birth to Six Steering Committee (Washington State); National Center for Clinical Infant Programs -- Project Birth to Three
Care Facility: University of Washington Child Development and Mental Retardation Center and Children's Hospital and Medical Center -- Seattle, WA
Skills and Interests: Developing programs in local schools and cooperatively across school districts
Experience: Local School Board Member; limited public speaking; advocacy for children
Related Employment: Teacher

Cassie Johnston
6138 Waldon Drive S.E.
Olympia, WA 98503
206 456-6310

Child's Disabilities: Developmental apraxia (08/19/81)
Affiliations: Birth to Six State Planning Project -- Parent Participant Coordinator; Parent-to-Parent of Olympia; *PAVE -- Community Liaison; Birth to Three Network; Wee Care Coalition
Care Facility: School District
Skills and Interests: Early intervention; respite care
Experience: Interagency advisory council; special tasks forces; working with health department; starting or maintaining parent/family support groups; public speaking; training parents, health care providers, and teachers; promoting legislation
Related Employment: Community Liaison, *PAVE; Parent Participant Coordinator, Birth to Six State Planning Project

Collette and Kim Juretich
16610 48th Avenue, W.
Lynnwood, WA 98037

Child's Disabilities: Down syndrome (02/08/83 to 09/21/89)
Affiliations: Parent to Parent of Utah -- former Coordinator
Skills and Interests: Willing to talk to other parents who have lost child with disability
Experience: Collette -- worked to pass a state mandated preschool bill in Utah, before the federal mandate passed; Kim -- serving on the ICC in Utah; starting or maintaining parent/family support groups; public speaking; training parents, health care providers, or teachers; promoting legislation

Charlene Monuszko
9844 South 262nd Place
Kent, WA 98031
206 854-6027

Children's Disabilities: Down syndrome (05/18/83); Static encephalopathy; spastic dysplasia (06/28/78); Two other children have static encephalopathy; dyspraxia; apraxia; attention deficit disorder (11/30/80 and 10/06/84)
Affiliations: Communities Environment and Families Group; *Parents Advocating Vocational Education (PAVE); South King Family Support Group; South King Family Resource Network
Care Facility: Speech, occupational, and physical therapy provided at home by visiting therapists because of high number of therapy hours required by four children
Skills and Interests: Developing parent professional partnerships; educating consumers to work with insurance companies and medical professionals; advocacy; community capacity building; inclusive schools and communities
Experience: Public speaking; promoting legislation; developed a training workshop for parents regarding medical advocacy and maintaining positive relationships with health professionals; organizer of Special Needs Resource Fair

Dennis Olson
115 Middle Street
Olympia, WA 98501
206 586-3007
206 357-3120

Child's Disabilities: Severe emotional disability (08/04/70)
Affiliations: Olympia Family Resource Network -- Project Officer; Family Resource and Support Project (Olympia Branch) -- Co-leader and Consultant; *Parents Advocating Vocational Education (PAVE)
Care Facility: Community-based residential program through the State Department of Social & Health Services
Skills and Interests: Integration of community resources and cross-system collaboration; community development; innovative respite alternatives; parent-professional collaboration
Experience: Serving as liaison between Federal CASSP project and 0-6 project at state level; working in health department to change the way mental health services are delivered to children and their families; working to bridge the categorical services of education, child welfare, health, juvenile justice, etc.; starting or maintaining parent/family support groups; public speaking; training parents, health care providers, and teachers; promoting legislation
Related Employment: Administrator, Child and Adolescent Service System, State Department of Social and Health Services, Mental Health

WEST VIRGINIA

Joyce F. Altizer
4613 Sixth Avenue
Vienna, WV 26105
304 295-5435

Child's Disabilities: Multiple congenital disabilities
Affiliations: We've Been There
Skills and Interests: Parent-to-parent support; workshops for health professionals on improving services; early childhood/special education
Experience: Serving on State Interagency Committee for Preschoolers with Handicaps; public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining parent/family support groups; working with state health departments

Peggy Proudfoot O'Brien
917 St. Joseph Street
Morgantown, WV 26505
304 293-7331
304 599-4655

Child's Disabilities: Cerebral palsy (11/15/71)
Care Facility: West Virginia University/Ruby Memorial Hospital -- Morgantown, WV
Skills and Interests: Home-based services; family empowerment
Experience: Developing West Virginia State Policy on "Witholding Medically Indicated Treatment From Disabled Infants with Life Threatening Conditions;" program development and resource materials development; starting or maintaining parent/family support groups; public speaking; training parents and health care providers; promoting legislation
Related Employment: Health Education Specialist, Klingberg Center for Child Development

Julie Parsons
6 Dartmouth Road
Morgantown, WV 26505
293-7331
599-0250

Child's Disabilities: Down syndrome (10/14/55)
Affiliations: Easter Seal Center -- Parent Support Group; Klingberg Center for Child Development -- Parent Consultant
Care Facility: W.G. Klingberg Center -- Morgantown, WV
Skills and Interests: Parent empowerment in advocacy
Experience: ACES (Advisory Council for Exceptional Children); public speaking; training parents
Related Employment: Parent trainer, Parent Educator Resource Center

Carrie Westbrook
Route 6 Box 244-M
Morgantown, WV 26505
304 293-7331
304 594-2068

Child's Disabilities: Cerebral palsy (03/29/86)
Affiliations: Monongalia County Easter Seal Support Group -- Co-coordinator
Care Facility: W.G. Klingberg Center for Child Development -- Morgantown, WV
Skills and Interests: Empowering parents in advocacy
Experience: ACES (Advisory Council for Exceptional Students); West Virginia Committee for Children with Special Needs; Monongalia County Ad-Hoc Interagency Group; starting or maintaining parent/family support groups; public speaking; training parents, health care providers, or teachers; promoting legislation
Related Employment: Parent Consultant, W.G. Klingberg Center for Child Development

WISCONSIN

Howard and Pam Erlanger
3902 Plymouth Circle
Madison, WI 53705
608 263-7405
608 238-0475

Child's Disabilities: Spinal cord tumor (1970)
Care Facility: University Hospital -- Madison, WI
Skills and Interests: Parent advocacy
Experience: Public speaking
Related Employment: Pam -- Occupational therapist; Howard -- Professor of law

Julie J. Gordon
150 Custer Court
Green Bay, WI 54301

Child's Disabilities: Cerebral palsy (spastic quadriplegia); mental retardation; autism; non-verbal
Affiliations: Mothers United for Moral Support (MUMS) -- Founder and President; Independent Living Council Member; Advocacy Coalition -- Legislative Committee
Care Facility: Webster Clinic -- Green Bay, WI
Experience: Subcommittee for the Interagency Coordinating Council for 99-457; Parent Education Project Council; Frell Citizenship Initiative Task Force; Cerebral Palsy Inc. -- Board Member; Curative Rehabilitation Center -- Corporate Board; starting or maintaining parent/family support groups; public speaking; training parents, health care providers, or teachers; promoting legislation

Leslie Grant and William Schwab
14 Rough Lee Court
Madison, WI 53705
608 231-1220

Child's Disabilities: Cerebral palsy; seizure disorder (01/02/83)
Affiliations: Univeristy of Wisconsin -- William -- Faculty member in Department of Family Medicine
Care Facility: University of Wisconsin Hospitals and Clinics -- Madison, WI
Skills and Interests: School issues for children with special health care needs; orienting home health and community caregivers and organizations; parent/professional collaboration; family-centered care in medical schools
Experience: Starting or maintaining parent/family support groups; public speaking; training parents, health care providers, and teachers; promoting legislation
Related Employment: William -- Physician, Department of Family Medicine, University of Wisconsin

Mary Hawley
RR 1, Box 125A
Superior, WI 54880
715 399-2127

Child's Disabilities: Vitamin D resistant rickets (familial hypophosphatemic rickets) (11/13/86)
Care Facility: University of Minnesota -- Minneapolis, MN
Skills and Interests: Starting support group and newsletter for children who have, and adults who have had, VDRR

Rhonda Katz
1832 Rowley Avenue
Madison, WI 53705
608 233-0985

Children's Disabilities: Twins -- Cerebral palsy; spasitc diaplegia; cognitive impairment; seizure disorder (10/18/85)
Affiliations: "Catalyst" (information and referral service for families in Dane County) -- Co-founder
Care Facility: Wausman Center for Developmental Disorders -- Madison, WI
Skills and Interests: Family support
Experience: Birth to 3 Project -- Parent Advisory Committee; starting or maintaining parent/family support groups; public speaking; training parents, health care providers, or teachers
Related Employment: Parent Coordinator, Development Assessment Clinic -- Madison, WI

Valerie Schreiner
203 Brookfield Drive
Stratford, WI 54484
715-687-4551

Child's Disabilities: Short bowel syndrome; seizure disorder; liver disease
Affiliations: PEN Parent Network -- Founder
Care Facility: Marshfield Clinic -- Marshfield, WI
Skills and Interests: Parent-to-parent support; working with families after hospital discharge; parent networking around nutrition programs
Experience: Starting or maintaining parent support groups; founding the Parenteral/Enteral Nutrition (PEN) Network for families of children on parenteral and/or enteral nutrition
Related Employment: R.N.

Terry and Terry Schwantes
1725 Lakeview Avenue
South Milwaukee, WI 53172
414-359-9800 (husband)
414-224-1474 (wife)
414 764-7421

Child's Disabilities: Osteogenesis imperfecta III (04/09/80)
Affiliations: Osteogenesis Imperfecta Foundation -- Legislative Committee
Care Facility: National Institutes of Health -- Bethesda, MD
Skills and Interests: Early intervention
Experience: Working with state department of education to mainstream children with OI; writing and publishing a booklet to provide parents with framework for enhancing their child's early development; starting or maintaining parent/family support groups; public speaking; training parents, health care providers, or teachers; promoting legislation

Mary Wilson
N978 Highway J
Lyndon Station, WI 53449

Child's Disabilities: Mental retardation (05/27/78)
Affiliations: Governor-appointed member of Wisconsin Council on Developmental Disabilities; Wisconsin Full Citizenship Initiative; ACCH; Wisconsin Nurses Association; Enrolled member of the Sioux and Ojibwa Nations (father Sioux, mother Ojibwa)
Skills and Interests: Parent networking; substance abuse counseling; organization support; needs and advocacy of children with developmental disabilities
Experience: WINGS Project Advisory Board; Juneau County Family Support Advisory Board
Related Employment: Home nursing of adults and children with disabilities; Respite care

WYOMING

Catherine Benitz
Box 253
Mt. View, WY 82939
307 782-6601
307 782-7513

Child's Disabilities: Bronchopulmonary dysplasia; developmental delays (04/23/86)
Care Facility: Primary Children's Medical Center, University of Utah -- Salt Lake City, UT
Skills and Interests: Early intervention and developing more community based services for families of children; informal parent-to-parent support for families of children with similar concerns
Experience: Serving as Chairwoman for the Wyoming Interagency Coordinating Council for P.L. 99-457; public speaking; training teachers; promoting legislation; working with the state health department
Related Employment: Regional Director, Lincoln-Uinta Child Development Association (regional preschool developmental disabilities program)

CANADA

BRITISH COLUMBIA

Valerie L. Brotherton
P.O. Box 2195
Sechelt, BC V0N 3A0
604 885-7033
604 885-2910

Child's Disabilities: Kasabach-Merritt syndrome; cavernous hemangioma (deceased)
Affiliations: Network for Kasabach-Merritt Syndrome -- Founder
Care Facility: Children's Hospital -- Vancouver, BC
Skills and Interests: Parent-to-parent support; establishing parent network

Sandra Williams
1790 Kilpatrick Avenue
Courtenay, BC V9N 2Y6
604 338-8879

Child's Disabilities: Congenital heart disease (05/01/81)
Affiliations: Y.A.N.A. (You Are Not Alone) -- Founder
Care Facility: Children's Hospital -- Vancouver, BC
Skills and Interests: Providing funding for families leaving Comox Valley for medical care; psychoscial effects of hospitalization on families; networking with local hospitals; fundraising
Experience: Public speaking; leading training for health providers and teachers; starting or maintaining support groups; working with provincial health departments

NEW BRUNSWICK

Pamela Carter
14 Glenview Avenue
Saint John, NB E2H 2G5
506 633-9113
506 696-5221

Child's Disabilities: Heart defects (09/26/84 to 09/10/88)
Affiliations: Parents for Parents -- President; Saint John Regional Hospital -- Volunteer, Parents for Parents Support Group
Care Facility: Saint John Regional Hospital and the Izaak Walton Killam Hospital -- Halifax, NS
Skills and Interests: Improving the hospital referral system
Experience: Starting or maintaining parent/family support groups; public speaking

Gloria Langille
35 Glendalea
Moncton, NB E1E 1E2
506 384-1428

Child's Disabilities: Cancer (ANLL)
Affiliations: Canadian Cancer Society of New Brunswick -- Patient Services Committee; Candlelighters Childhood Cancer Association of New Brunswick, Moncton Chapter -- Coordinator and Chairperson; Moncton Hospital -- Cancer Patient Liaison Group
Care Facility: Izaak Walton Killam Hospital -- Halifax, NS
Skills and Interests: Home visiting programs; home tutoring and school counseling services for children who cannot attend school regularly; improving the quality of pediatric care in a general hospital; the sensitivity of communications between health professionals and families; parent-to-parent support; parent advocacy
Experience: Working with the education department to continue funding for home tutors and school counselors for children with chronic illness; working with the local general hospital to make the IV treatment regime more sensitive to the needs of children with cancer and thie families and to improve the quality of communications between health professionals and families; starting or maintaining parent/family support groups

NEW FOUNDLAND

Sylvia Mackey
841 Daigle Crescent
Labrador City, NF A2V 2E3
709 944-5620

Child's Disabilities: Cerebral palsy
Affiliations: Canadian Association for

Community Living
Care Facility: Isaac Walton Killam Hospital for Children -- Halifax, NS
Skills and Interests: Cerebral palsy education for public and professionals
Experience: Public speaking; starting or maintaining parent/family support groups; working with department of social services as a foster parent to a child with special needs

NOVA SCOTIA

Dina Dickson
300 Micmac Boulevard, #318
Dartmouth, NS B3A 4L6
902 466-3332

Child's Disabilities: Leukemia
Affiliations: Maritime Candlelighters Childhood Cancer Foundation -- Vice President
Care Facility: Izaak Walton Killam Hospital for Children -- Halifax, NS
Skills and Interests: Parent support; fundraising; planning family activities and monthly meetings
Experience: Public speaking; starting or maintaining parent/family support groups; bereavement support

Elaine and Manuel Ribeiro
Site 14, Box 100, RR #2
Windsor Junction, NS B0N 2V0
902 861 2379

Child's Disabilities: Partial Monosomy, 18q (01/86)
Affiliations: Sackville-Bedford Developmental Center
Care Facility: Izaak Walton Killam Hospital for Children and Dalhousie Family Medicine -- Halifax, NS
Skills and Interests: Improving delivery of various health care and educational services presently available in Nova Scotia; more funding for services that are not available, such as respite
Experience: Public speaking
Related Employment: Teacher, Nova Scotia Community College, I.W. Akerley Campus
Languages other than English: Chinese; French

ONTARIO

Mary Gabriele
68 Squire Graham Lane
Woodbridge, ON L4L 7C5
416 856-2737

Child's Disabilities: Goldenhar syndrome; bilateral cleft lip & palate (10/31/86)
Affiliations: About Face -- Coordinator, Toronto Chapter
Care Facility: Toronto Hospital for Sick Children
Skills and Interests: Public awareness; awareness in school-age children
Experience: School programs; starting or maintaining parent/family support groups

Elaine Orrbine
155 Owl Drive
Ottawa, ON K1V 9J5
613 737-4098
613 526-4242

Child's Disabilities: Nephrotic syndrome (02/12/75)
Affiliations: Kidney Foundation of Canada; Children's Hospital of Eastern Ontario Foundation
Care Facility: Children's Hospital of Eastern Ontario -- Ottawa, ON
Skills and Interests: Coordination and development of support group for parents and children with Nephrotic Syndrome
Experience: Author of two handbooks for parents: *Childhood Nephrotic Syndrome, You and Your Child* and *Understanding Kidney Failure* (both are available in English and French); public speaking; starting or maintaining parent/family support groups
Related Employment: Research Coordinator, Canadian Pediatric Kidney Disease Reference Centre, Children's Hospital of Eastern Ontario

Jane Elizabeth Richardson
37 Brookfield Boulevard
Dunnville, ON N1A 3G2
416 774-8853

Child's Disabilities: Cleft lip & palate (01/11/87)
Affiliations: About Face -- Board Member, Program's Chairwoman, and Coordinator, Hamilton Area Chapter; Easter Seals Society -- Parent Delegate
Care Facility: Chedoke-McMaster Medical Centre -- Hamilton, ON
Skills and interests: Early intervention
Experience: Developing Cleft Care Kit; helping to design training program for support persons involved with newborn support, hospitalization support, and family support; designing training program for creating new About Face chapters; starting or maintaining parent/family support groups; public speaking; training parents and health care providers
Related Employment: Volunteer; Support Parent Contact, Cleft Lip & Palate Team, Chedoke-McMaster Hospital

Index of Names

Nancy Abernathey 87
Kathleen Adams 44
Mark and Ramona Adams .. 44
Kent S. Alberty 78
Donna G. Albrecht 8
Chris and Sharon Albright ... 3
Rosemary Alexander 80
John A. and Pamela K. Allen 55
Joyce F. Altizer 94
Lana Ambler 91
Dell B. Amos 35
David R. Buckholtz and
 Karen Crawley-Buckholtz .. 39
Betsy Anderson 42
John and Polly Arango 58
Dorothy Arlt 68
Ray and Loretta A. Armenta 58
Jane Armfield 8
Debra R. Asselin 87
Anne Bakeman 87
Tanya Baker-McCue 88
Dana Baldridge 71
Lucinda Barker 62
Judy Barnes 45
Candee Basford 68
Jonathan and Kathie Basten . 19
Trisha Beck 86
Julie Beckett 30
Charlotte Bell 3
Catherine Benitz 97
Sandra Bennett 80
Rebekah Berman 45
Kay Biescar 80
Barbara Bilyeu 93
Lesly Bird 8
Sharon Bishop 72
Carol R. Blades 3
Hilary Blake 63
Catherine Blevins 80
Brenda and David Blizzard . 53
Craig and Ruth Bolinger ... 30
Darlene Bonavita 16
Mary Bonsignore 63
Rochelle S. Boomhower 88
Margaret V. Bordonaro 63
Priscilla Bradway 42
Beverly Branscum 34
Ronald and Rena Breaux ... 35
Kathleen Brehm 74
John and Lynn Brennan 88
Jacqueline Bressers 5
Denise Briley 35
Valerie L. Brotherton 98
Ardith F. Brown 17
Gayle B. Brown 34
Jennifer Brown 68
Joanne C. Brownlie 6
Jane Morrison Bubar 38
Betty Burton 43
Beverly Butler 35
Jo Butts 93
Lynsee and Robert Cain 8
William and Terri Cameron . 39
Kathy F. Campbell 21
Marie Capobianco 63
Emma K. Cappadonna 21
Maria E. Cardona 81
Pamela Cardoso 79
Dawn Curlee Carlson 27
June Carrin 9
Pamela Carter 98
Joan Cassel 9
Pam Chadwick 9
Joan and Jeremy Chess 63
Susan Colburn 3
Molly P. Cole 14
Rosalind I. Coleman 16
Loretta Collins 74
Sheila K. Collins 39
Virginia Conlee 78
Donna M. Connell 34
Colleen D. Conner 21
Valerie M. Constance 45
Katherine and James Cooper 39
Ann Cosby 3
Diana Cuthbertson 56
Mary Lou Cutrera 36
Sue Dailey 59

Index of Names

Myra T. Daquioag 22
Debi S. Daughn 81
Connie L. Daviet 14
Deborah Davis 54
Blenda Davis 25
Yvonne De Paepe 45
Nancy Dean 79
Deb House Deere 31
Christy Dees 81
Dina Dickson 99
Linda Diffine' 6
Judy Dinofrio 74
Nancy DiVenere 88
Diana J. Dowling 54
Pat Downey 40
Vicki F. Draper 93
Kimberly A. Duke 68
Bonnie and Skip Dunham .. 55
Silvia Dunne 45
Robert L. Dunning 81
Dorothy and Walter Dustmann 40
Linda Dutton 74
Elsie Edge 73
Beth Edmands 5
Faye Manaster and Artur Eldar 26
Jackie and Bob Ellerbrock .. 68
Beth Eloe-Reep 25
Lorie Emmons 36
Katherine Erickson 67
Howard and Pam Erlanger .. 95
Paul and Judy T. Essex 64
Manuela Estrada 26
Janet Evans 17
Ann K. Farr 79
Carol Farris 69
Ellen Feifarek 40
Sue Ferguson 91
Connie Fischer 46
Charles and Marilyn Fiske .. 43
Tim C. and Laura Fitzgerald 36
Dawne Flammger 64
Annette Fogleman 17
Janice Foreman 81
L. Bryn Fortune 46
Paul and Marilyn Fox 9
Linda Fox 43
Christina C. Fox 64
Lorena Freund 25
Mary Gabriele 99
Patrick Alan and Karen Sue Gaffner 46
Catherine Gaines 59
Deborah Garcia 59
Joan Gebo 17
Coleen Geyer 75
Rose Anne Gilbert 36
Anne B. Gildea 65
Barbara Ginsburg 75
Carolyn Gire 22
Mary and Jim Goldsack 79
Cheryl and Richard Goldschmidt 75
Mari Gooch-Bauhofer 9
Valerie R. Goodwin 82
Julie J. Gordon 95
Page Talbott Gould 75
Mr. and Mrs. Roger Grandy . 75
Leslie Grant 95
Frank Graziadei 66
James Green 27
Mary Regina Grochmal 40
Ursula C. Guy 40
Dianne L. Haas 47
Elaine and Walter Hackett .. 69
Pat Hackett-Waters 17
Larry and Lyn Hafner 31
Linda Hankins 28
Patricia and John Hanley ... 47
Carol S. Harley 77
Marlene R. Harrington 21
JoAnn B. Harris 10
Janet Hawes 69
Mary Hawley 96
Mr. and Mrs. John Hedge .. 69
Joe and Marirene Heisler ... 57
Mark and Jane Henkel 48
Jody W. Hill 22
Charlie & Suzi Hillman 89
Jewetta and Vernon Himes . 82

Janet Hine 15
Mary Ellen McCain and Barry Hoffman 36
Louise Hoffman 3
Brenda Holmes-King 4
Barbara Hopkins 6
Patty Houghland 18
Beverly Houston 60
Denny Hoyt 31
Steve and Dorothy Hull 82
Doris Husted 59
Caroline C. Hyde 38
Margaret Ieronimo 27
Carolyn Craig and Eric Ingbar 55
Claudia and Dan Ippolito 28
Jean Isaacs 34
John and Pam Jackson 89
Jennifer Jackson 70
Sharman Davis Jamison 48
Wayne and Amy Jasper 10
LuAnn Jelinek 48
Patti Jennings 60
Diana L. Johnson 48
Gail D. Johnson 40
Lourdes Johnson 82
Martha J. Johnson 60
Cynthia Johnson 70
Kathy Johnson 33
Edith P. Johnson 91
Faye Johnson 4
Cassie Johnston 93
Monica Loose Jones 10
Joyce Jones 28
Collette and Kim Juretich 93
Gordon K. Kakalia 22
Karen Ululani Kameenui 22
Gail Posner and Harry Karp 31
Suzanne Kashiwaeda 23
Rhonda Katz 96
Anna Belle Kaufman 10
Katharin A. Kelker 53
Lora A. Keller 10
Dawn Kellogg 78
Ruth Kimberley 28
Lavonna King 34
Steven and Anita Klein 16
Margaret Knapp 89
Cheryl Knight 21
Bruce and Diana Koppenhoefer 4
Pam Kourafas 73
Shirley A. Kramer 49
Rita A. Kukura 72
Pam Meyer Kunkle 76
Paula Lalinde 18
Linda and Pierre Landry 11
Bill and Valeri Lane 52
Gloria Langille 98
Susan Larkin 6
Colette Lau 83
Anne M. Lauritzen 54
Carla Lawson 32
Shelly LeBlanc 37
Peggy P. LeBlanc 36
Robin LeFrak 11
Linda Lemons 80
Marion T. Leong 23
Suzanne B. Levy 76
Audrey Lewis 27
Carol Lichtenwalter 70
Arnold L. and Joyce E. Lindgren 49
Ronnie Londner 18
Peter and Eileen Losi 57
Kayleen C. Lowe 5
Cindy Lucas 91
Lynda Macha 70
Jan Mackey 32
Joanne Mackey 66
Sylvia Mackey 98
Miftah H. MacNeil 11
Martha-Jean and Robert Madison 56
Paula Scott Malia 23
Anne Martin 57
Dolorita Massiah 91
Diana Sue Mathews 19
Rita and David Matthews 83
Carmen Maya 27
Cheron J. Mayhall 73

Index of Names

Marijo McBride 49
Stan and Debbie McCaffrey . 51
Beverly McConnell 47
Mary McFarland 53
Preston McPhail 72
Mr. & Mrs. Ronald Medler . 19
Sally Meersman 11
Margaret Mikol 64
Lucia Milburn 12
Elizabeth Milizia 89
Shirley Jones Miller 51
Becky Millsap 71
Maureen Mitchell 89
Roberta Longhi Montetta ... 64
Charlene Monuszko 94
John and
 Nancy Moreno-Derks 12
Nancy Morgan 7
Nancy M. L. Munson 28
Lynne and
 Thomas Murphy 43
Donna Naclerio 60
Mary Nakasuji-Yoshino 23
Minna Newman Nathanson . 16
Kathy Neno 4
John and Pattie Nishimoto .. 23
Ruth Norton 15
Cindy Norwood 71
Peggy Proudfoot O'Brien ... 94
Kevin O'Sullivan 38
Kathy Odle 51
Terry Ohlson 56
Donna Olsen 29
Dennis Olson 94
Elaine Orrbine 99
Nancy S. Ott 78
Eileen Ouellette 91
Elizabeth Padilla 61
Claudia and Ed Pagani 65
Ellen Parker 12
Beverly Parks 34
Julie Parsons 95
Jeanie Pemberton 83
Susie Perrett 86
Marshall and Susan Peter ... 73
Leau A. Phillips 61
Diana Buder Phillips 83
Mary Spalding Picchi 12
Sherry S. Pierce 38
Vickie D. Polk 21
Barbara Popper 43
Andrea Portente 57
Brenda Potter 66
Lynn Powell 12
Florene Stewart Poyadue ... 13
Beverly Preske 29
Anne Presley 52
Michael D. and
 Elizabeth D. Prince 4
Vonna Privett 91
Charlotte Provencher 83
Jane Purdy 92
Rashid and
 Martha Qureshi 84
Marcia Radin 47
Lea Ramsour 84
Brenda Rapp 84
Karen Rath 13
Christine Rawlings 26
Mary Lou Reaver 76
B.J. and Chris Reed 54
Helen Reisner 41
Jule Reynolds 32
Elaine and
 Manuel Ribeiro 99
Lynna Rice 53
Helena Gutierrez-Richards .. 77
Melynda Richards 86
Jane Elizabeth Richardson . 100
Patrice A. Richardson 77
Virginia Richardson 50
Pat Rieger 29
Amy Robinson 43
Susan Rocco 24
Donna Ross 76
Linda Rother 50
June H. Rouse 33
Rosalie N. Ruffin-Black 29
Paul F. and
 Susan L. Rump 90
Deborah Russell 48
Anne Russell 84

Index of Names

Nancy C. Samrow 37
Amita Sarin 41
Bonnie Schmid 78
Shannon Scholler 33
Valerie Schreiner 96
William Schwab 95
Terry and Terry Schwantes .. 96
Ellen M. Schwenk 78
Claudia Segal 41
Karen Shannon 41
Celia Shapland 50
Pleaman and Marci Shaver .. 24
Candy Sheehan 84
Pauline Sherman 44
Frank and Nicol Shulman ... 19
George and Bobbie Sich ... 71
Nana Silva 24
Rosemary Silversmith 61
Lawrence and Mary Singer .. 61
Lucienne D. Siragusa 37
Grace Adams Sisco 87
Sandra Slavet 44
Constance K. Smith 24
Patty Smith 92
Janis Smith 7
Vicki Sommers 85
David and Laura Soyster ... 74
Pam Spinney 90
Elizabeth Stanley 19
Cathy Stark 85
Barbara Staub 50
Sandy Steele 66
Kathy S. Stephens 72
Beth Stewart 67
David Stewart 5
Dorothy Stone 65
Georgette Strohm 13
Reggie Smolik Swindle 26
Emily Tarpley 16
Karen Taycher 55
Francine Templeton 85
Lynn Terry 5
Audrey F. Thomas 57
Cathie Thomas 61
Josie Thomas 42
Trish Thomas 62
Nancy Thompson 32
Jennifer Kay Thorne 62
Virginia M. Tipton 85
Patricia Tomka 15
Pam Tomsky 85
Jeffrey and Sally Toughill ... 58
Ruth Tracy 7
Betsy Trombino 7
Brenda Trumble 6
Kathy Tullos 52
Sally Van Curen 62
Becky Venice 74
Ronald and Judy Vessey 51
Elaine Viola 86
Janet Vohs 44
Dana Vouga 53
Gail Walker 76
Larry and Julie Walker 37
Frances Walsh 65
David and Shannon Ward 55
Dawn Wardyga 77
Leigh Ware 20
Gwen and Albert Wasden ... 5
Jeanne Watai 25
Katherine Ann Weaver 29
Greg and Lori Weigle 92
Connie Wells 20
Carrie Westbrook 95
Carol Whetsel 30
Gladys and Ben Whitehouse 67
Joan Whitten 15
Nancy Wilks 20
Linda E. Williams 13
Sandra Williams 98
Dorothy Williams 13
Mary Wilson 96
Val Wilson 67
Dorie Winquist 30
Beth Witt 38
Josie Woll 25
Marilou Wright 86
Linda Wurzbach 14
Susan Yuan 90

Index of Disabilities

Agenesis of the corpus callosum ... 15, 43
AIDS/HIV infection ... 9, 10, 54
Allergies ... 29, 46, 61, 74, 81
Alpha-1-antitrypsin deficiency ... 9, 62
Amputation ... 21
Anal stenosis ... 9
Angleman syndrome ... 89
Anoplasty ... 9
Anoxia ... 64
Apert syndrome -- see Craniofacial disfigurement
Aplastic anemia -- see Cancer
Apnea ... 39, 47, 50
Apraxia ... 62, 93-94
Arnold-Chiari syndrome (see also Spina bifida) ... 3, 52, 91
Arthritis ... 27, 49, 74
Asthma ... 13, 17, 29, 36, 46, 59-60, 70, 74
Astrocytoma brain tumor -- see Cancer
Attention deficit disorder (ADD)/Hyperactivity ... 9, 20-21, 48-49, 60, 63, 71-72, 79, 82, 92, 94
Autism ... 19, 25, 27, 31, 40, 48, 59, 60, 63, 68, 71, 77, 81, 83-84, 87, 91, 95
Autonomic dysfunction ... 20
Batten disease ... 11, 40
Blindness -- see Visual impairment/Blindness
Bowel impaction ... 45
Brain damage ... 5, 18, 23, 38, 45, 53, 64, 72, 76-77, 86
  Closed brain injury ... 13
  Degenerative brain disorder ... 77
  Head injury ... 73, 80, 82, 84
C-Syndrome ... 72
Camptomelia -- see Short stature
Cancer ... 56
  Aplastic anemia ... 69
  Astrocytoma brain tumor ... 24
  Leukemia ... 16, 45, 77, 81, 83, 85, 98, 99
  Neuroblastoma ... 72
  Rhabdomyosarcoma ... 67, 79
Cardiac impairment ... 6, 13, 58
  Aortic stenosis ... 22
  Atrial septal defect ... 40
  Congenital heart defect ... 14, 22, 59, 91, 98
  Hypertrophic cardiomyopathy ... 4
  Interrupted aortic arch ... 30
  Intraventricular hemorrhage (IVH) ... 18, 49

  Tetralogy of Fallot ... 36
  Transposition of the great vessels ... 24
  Ventricular septal defect (VSD) ... 9, 61
Cavernous hemangioma ... 98
Central alveolar hypoventilation -- see Respiratory disorder
Cerebellar dysgenesis ... 15
Cerebral agenesis ... 25, 56
Cerebral palsy ... 5, 6, 10, 15-19, 21-22, 24, 26, 29, 31-36, 38-42, 44-45, 47-50, 55-56, 58-60, 62-66, 70-76, 78-80, 84, 88-89, 91-96, 98
Chromosome syndrome ... 80
Cleft lip and palate ... 6, 11, 23, 25, 37, 42, 48, 53, 68, 77, 79, 85, 99-100
Club foot ... 68
Cobalamin E -- see Metabolic disorder
Congenital adrenal hyperplasia ... 48
Congenital fibertype disproportion ... 54
Cornelia de Lange syndrome ... 12, 59
Craniofacial disfigurement ... 83
  Apert syndrome ... 91
  Craniosynostosis ... 63, 65
  Goldenhar syndrome ... 99
  Hemifacial microsomia ... 42
Cri-du-chat syndrome ... 35
Cystic fibrosis ... 29-30, 36, 84, 88
Cytomegalovirus (CMV) ... 35, 42
Deafness -- see Hearing impairment/Deafness
Developmental delay ... 4, 5, 8-9, 17, 22, 25, 30-31, 36, 61, 69-70, 73, 75, 78, 84-85, 91, 97
Developmental disorder ... 24, 40
Diabetes ... 5, 73
Diaphragmatic hernia ... 43, 64
DiGeorge syndrome ... 30
Down syndrome ... 3, 5-7, 9, 12-13, 19, 21, 24, 26-28, 32-33, 38-40, 44-45, 53, 55-56, 58-61, 66-68, 70, 74-75, 81-82, 85-86, 89-90, 92-95
Dwarfism -- see Short stature
Dyslexia ... 85, 91
Dysphasia ... 63
Ehlers-Danlos syndrome ... 77
Emotional/Behavioral disorder ... 27, 34, 51, 56, 62, 83, 85, 88, 94
Encephalitis ... 30, 36
Encephlocele ... 73
Enchnodromatoses -- see Ollier disease
Encopresis ... 88
Epilepsy/Seizure disorder ... 4-5, 7, 11, 13, 18-24, 29, 31-34, 36-38, 41, 47-50, 55, 58, 60-61, 64, 66, 70, 75-78, 80-81, 84-85, 90-92, 95-96
Facial nerve paralysis ... 43

Failure to thrive 22, 45, 78, 92
Fetal alcohol syndrome 39
First branchial arch syndrome 75
Fragile X syndrome 28
Gastroesophageal reflux 7, 17, 37, 48, 66, 70
Gastrostomy 7, 9-10, 13, 18, 31, 45, 51, 60, 64, 66, 78-79
Goldenhar syndrome -- see Craniofacial disfigurement
Growth disorder 47, 61
Hearing impairment/Deafness 3, 9, 11, 24, 26, 32, 41-42, 48-50, 54-56, 60-63, 66, 68-70, 73, 77-78, 81-82, 86-87
Hemifacial microsomia -- see Craniofacial disfigurement
Hemiplegia -- see Paralysis
Hip dislocation 19, 66
Hirschsprung's disease 21, 45, 49, 64
Histiocytosis/Langerhans cell histiocytosis 58
Hormone deficiency 79
Hunter syndrome 22, 28, 63
Hyaline membrane disease 4
Hydrocephalus (see also Spina bifida) 3, 14, 25, 30, 36-38, 49, 52, 54, 61, 66, 73, 84, 91
Hydromyelia 91
Hyperactivity -- see Attention deficit disorder (ADD)/Hyperactivity
Hypertelorism-hypospadius syndrome 32
Hyperthyroidism 56
Hyperverbalism 30
Hypopanpituitaryism 24
Hypospadius 9
Hypothyroidism 76
Hypotonia 31, 44, 50
Hypsarrhythmia 38
I-cell disease -- see Metabolic disorder
Ichthyosis 78
Illiostomy 32
Immune deficiency 17
Incepitis 5
Incontinentia pigmenti 48
Interstitial 2q minus 66
Intestinal impairment 61
Juvenile neronal ceroid lipofucinosis -- see Batten disease
Kasabach-Merritt syndrome 98
Kawasaki disease 19
Ketotic hypoglycemia -- see Metabolic disorder
Kidney disease 12, 44
  Hydronephrosis 91
  Nephrotic syndrome 99
  Renal failure 61

Klippel-Trenaunay-Weber (K-T) syndrome 51, 58
Kniest syndrome 87
Kyphosis 16, 36, 49, 68
Lactic acidosis 90
Learning disability 6, 8, 13-14, 20, 41-42, 46, 49-50, 56, 60, 62, 66, 68, 73, 81, 85-86, 88, 92-93
Leukemia -- see Cancer
Leukodystrophy 7, 45
Limbless 36
Lissencephaly -- see Miller syndrome
Liver disease 96
Lowe's syndrome 74
Mannosidosis 46
Marshall-Smith syndrome 78
Medical fragility 32, 48, 49
Mental retardation 4, 7, 12, 15, 19-20, 23-24, 32, 34-35, 38-39, 41, 47-48, 50, 53, 55, 59-60, 63, 65-66, 68-70, 75, 77, 79-81, 83, 89, 92, 95-96
Metabolic disorder 46, 59
  Cobalamin G 90
  I-cell disease 25, 40
  Ketotic hypoglycemia 52
Microcephaly 60, 61, 78
Miller syndrome 27, 31, 50
Moebius syndrome 88
Monosomy 3P26 11
Mucocutaneous lymph node syndrome -- see Kawasaki disease
Mucolipidosis 40, 63
Mucopolysachridosis -- see Hunter syndrome
Mucopolysachridosis sanfilipo B 25
Muscle fiber disproportion 11
Muscular dystrophy 68-69
  Duchenne muscular dystrophy 29, 66
Myelomeningocele -- see Spina bifida/Myelomeningocele
Nager's syndrome 9
Nemaline myopathy 6
Nephrotic syndrome -- see Kidney disease
Neuroaxonal dystrophy 51
Neuroblastoma -- see Cancer
Neurofibromatosis 21, 43
Neurological impairment 3, 47
Neurological disease (possible result of Pertussis vaccine) 82
Noonan's syndrome 4
Ollier disease 78
Organ transplant 43
Osteogenesis imperfecta 87, 96

Paralysis
  Hemiplegia 38
  Quadriplegia 7, 10, 37, 57, 65-66
  Spastic quadriparesis 64
Partial monosomy, 18q 99
Pernicious anemia 27
Persistent fetal circulation 4, 20
Phenylketonuria (PKU) 55
Post-polio sequelae 49
Prematurity 3, 9-10, 13, 15, 17, 22-23, 33, 40, 48-49,
56, 64, 67, 75, 86-87
Prenatal exposure to cocaine 9, 49
Prune Belly syndrome 6
Pseudo-obstruction of the intestinal track 8
Reflex sympathetic dystrophy syndrome (RSDS) 57
Respiratory disorder 6-7, 9, 22, 32
  Bronchopulmonary dysplasia 5, 9, 10, 17, 39, 60-61, 87, 97
  Central hypoventilation syndrome 8, 33, 65
  Obstructive/restrictive airway disease 61
  Pulmonary hypertension 8, 61
  Pulmonary stenosis 24
Retinapothy of prematurity 15
Rett syndrome 23, 35, 63
Rhizomelic chondrodysplasia punctata 86
Rickets 96
Rubella syndrome 4, 24, 63, 67
Rubinstein-Taybi syndrome 12, 39
Scoliosis 6-7, 16, 25, 36, 48-49, 66, 68-69, 81
Seizure disorder – see Epilepsy/Seizure disorder
Short bowel syndrome 54, 86, 96
Short stature
  Camptomelia 34, 83
  Dwarfism 7, 68
SIDS (Sudden Infant Death Syndrome)
  near-SIDS 17, 53
Smith-Lemli-Opitz syndrome 44
Speech/Language impairment 8-9, 17, 36, 44, 46-47,
51, 62, 65
Spina bifida/Myelomeningocele 3, 14, 16, 18-19, 25-26, 28,
34-35, 37, 42-43, 49, 52, 54, 64, 66, 69, 71, 76, 79, 89, 91
Spinal cord tumor 95
Static dysplasia 94
Static encephalopathy 31, 78, 94
Stroke 75
Sturge-Weber syndrome 58, 93
Subglottic stenosis 39

Systemic lupus erythematosis 57
Technology dependence 56
  Ventilator dependence/assistance 8-9, 18, 30, 33, 37, 41, 45, 51-52, 57, 63-64, 87
Tourette syndrome 72, 76
Toxoplasmosis 43
Tracheal stenosis 48
Tracheomalacia 30, 39, 68
Tracheostomy 10, 13, 17-18, 45, 48, 79
Trisomy 4P 13
Trisomy 7 45
Trisomy 9 80
Trisomy 18 46
Trisomy 21H 44
Trisomy 22 45
Tuberous sclerosis 10, 73
Turner syndrome 16, 22
Ventilator dependence/assistance -- see Technology dependence
Visual impairment/Blindness 4-5, 11, 15-16, 22, 24, 26, 36, 38, 41, 47, 49, 54-56, 60-62, 66, 70, 76-77, 79, 89
  Optic atrophy 30
Vocal cord paralysis 48, 61
Von-Hippel Lindau Syndrome 57
Werdnig-Hoffmann disease 8, 10, 17, 27-28, 32, 51, 80
Williams syndrome 11, 39, 45, 53, 57, 80
Wolf syndrome 89
49XXXXY syndrome 40

Index of Special Interests

This index is intended to help parents and professionals develop new programs and resources. When large numbers of parents describe interest or experience in the same areas, the index is of no real use. Therefore, these areas, which include early intervention, parent-to-parent support, health care financing/insurance, and home care, were omitted from the index. This index may not be all-inclusive, as it depends on how the information form was completed. Finally, if more than one parent on a page has the same interest or experience, the page number is given only once.

Adolescent issues 34, 58

Adoption/Foster care 5, 9, 22, 32, 34, 39-40, 42, 46, 49, 55-56, 58, 60, 62-63, 92, 99

Augmentative communication 52, 56, 59, 69

Bereavement and hospice 10, 11, 39, 46, 67, 77, 99

Care coordination 18, 31, 40, 42, 50, 52, 58, 65, 67, 91

Child care 10, 18, 31, 41

Computer assisted instruction 24, 50, 85

Cultural/Ethnic issues 5, 18, 20, 24, 49, 58, 60, 62

Ethical issues 14, 41, 77

Extended family support
  Brothers and Sisters 3, 9, 12-13, 42, 45, 52, 67, 79, 81, 83
  Fathers 31
  Grandparents 37

Fundraising/Grant writing 4, 9, 18-19, 21, 24, 34-36, 41, 45, 47, 51-52, 57, 58, 72, 75, 84, 88-89

Integration/Mainstreaming 5, 7, 11-13, 17-18, 33, 40-41, 44, 48, 50, 52-53, 56, 58-59, 62, 68-71, 74-75, 81, 85-86, 90, 94, 96

Interagency Coordinating Council (ICC) 3-6, 8, 11, 17-18, 20, 23-24, 29, 32, 36, 38-41, 43, 45, 47-49, 51-52, 54-55, 59, 61-62, 65- 67, 70-72, 78-79, 86, 90, 93-95, 97

Least restrictive environment 11

- Languages
  - Chinese 99
  - French 8, 10, 13, 38-39, 42, 48, 75, 99
  - German 5, 10, 18, 46, 83
  - Hebrew 26
  - Hindi 41
  - Japanese 23
  - Navajo 7, 61
  - Polish 26
  - Russian 26
  - Sign language 11, 25-26, 42, 44, 52, 73, 81-82, 87-88
  - Spanish 18, 22, 27, 42-43, 45, 57-58, 61, 63, 67, 69, 77, 80-82, 84
  - Swedish 49
  - Tagalog (Filipino) 22
  - Tewa 61
  - Urdu (Pakistani) 84
  - Yupik 5
- Libraries
  - Family Resource Libraries 13, 33, 52, 82-83
  - Toy Lending/Lekotek Libraries 53, 69
- Military issues 92
- Newborn intensive care unit (NICU) services 4-5, 13, 20, 22, 28, 34, 60, 75, 87
- Nutrition programs 19, 54, 59, 87, 96
- Parent-authored resources 10, 16, 19, 32, 38, 41, 67, 92
- Recreation/Camp programs 9, 15, 29, 37, 41, 46, 51, 80, 89
- Respite care 4-6, 8-11, 13, 15, 19-21, 24-25, 28, 31-32, 34-35, 39, 41, 44-47, 51-52, 54-56, 58, 63-66, 68, 71-72, 75-76, 78-82, 84, 86-94, 96, 99
- Ronald McDonald Houses 72, 79
- Rural services 30, 51-53, 59, 85, 92
- Substance Abuse 96
- Spiritual issues 31, 48, 66, 85
- Transition issues 4, 10, 18-19, 21, 33, 38, 51, 58-59, 72, 75-76, 81, 84-87, 93
  - Young children 16
  - Adolescence to adulthood 7, 16, 35, 68
  - Adult (including independent living) 15, 49, 56, 74, 95

Parent Training & Information Centers (PTIs)

All states have PTI funding at the time of printing, however, an updated list was not available. Please contact the Federation for Children with Special Needs at 95 Berkeley Street, Boston, MA, 02116, 617 482-2915 for the name of the PTI in your state if none is listed below.

Alabama

Special Education
Action Committee, Inc.
P.O. Box 161274
Mobile, AL 36606
205 4778-1208

Arizona

Pilot Parents, Inc.
2150 East Highland Avenue
Phoenix, AZ 85016
602 468-3001

Arkansas

Arkansas Coalition
for the Handicapped
519 East Capitol
Little Rock, AR 72202
501 376-3420

California

TASK
18685 Santa Inez
Fountain Valley, CA 92708
714 962-6332

Northern California Parent Training
and Information Coalition (NCC):

Parents Helping Parents
535 Race Street, Suite 200
San Jose, CA 95126
408 499-3877

Disability Rights
Education and Defense Fund, Inc.
2212 6th Street
Berkeley, CA 94710
415 644-2555

Disability Services Matrix
P.O. Box 6541
San Rafael, CA 94903

Colorado

PEAK
6055 Lehman Drive, Suite 101
Colorado Springs, CO 80918
719 531-9400

Connecticut

Connecticut Parent Advocacy Center
P.O. Box 579
East Lyme, CT 06333
203 739-3089

(for Federal Express, UPS:
5 Church Lane, #4)

Delaware

PIC of Delaware, Inc.
700 Barksdale Road, Suite 6
Newark, DE 19711
302 366-0152

Florida

Parent Education Network (PEN)/
Florida, Inc.
2215 East Henry Avenue
Tampa, FL 33610
813 238-6100

Georgia

Parents Educating Parents (PEP)
Georgia ARC
1851 Ram Runway, Suite 104
College Park, GA 30337
404 761-2745

Hawaii

Hawaii Association of Children
and Adults with Learning Disabilities
200 North Vineyard Boulevard, #103
Honolulu, HI 96817
808 536-9684

Idaho

Idaho Parents UNLTD., Inc.
6816 Fernwood Drive
Boise, ID 83709
208 377-2199

Illinois

Coordinating Council
for Handicapped Children
20 East Jackson Boulevard, #900
Chicago, IL 60604
312 939-3513

Design for Change
220 South State Street, #1900
Chicago, IL 60604
312 922-0317

Indiana

Task Force on Education
for the Handicapped, Inc.
833 Northside Boulevard
Building 1, rear
South Bend, IN 46617
219 234-7101

Iowa

Iowa Exceptional Parents Center
33 North 12th Street
P.O. Box 1151
Fort Dodge, IA 50501
515 576-5870

Kansas

Families Together, Inc.
4125 Southwest Gage Center Drive, Suite 200
Topeka, KS 66604
913 273-6343

Kentucky

Kentucky Special Parent
Involvement Network
318 West Kentucky Street
Louisville, KY 40203
502 587-5717
502 584-1104

Louisiana

United Cerebral Palsy
of Greater New Orleans
1500 Edwards Avenue, Suite O
Harahan, LA 70123
504 733-7736

Maine

Special Needs Parent
Information Network (SPIN)
P.O. Box 2067
Augusta, ME 04330
207 582-2504
800 325-0220 (ME only)

Maryland

The Parents' Place of Maryland, Inc.
7257 Parkway Drive, Suite 210
Hanover, MD 21076
301 379-0900

Massachusetts

Federation for Children
with Special Needs
95 Berkeley Street
Boston, MA 02116
617 482-2915
800 331-0688 (MA only)

Michigan

Service Department
United Cerebral Palsy/Detroit Community
17000 West 8 Mile Road, Suite 380
Southfield, MI 48075
313-557-5070

Citizens Alliance to
Uphold Special Education (CAUSE)
313 South Washington Square, lower level
Lansing, MI 48933
517 485-4084
800 221-9105 (MI only)

Minnesota

PACER Center, Inc.
4826 Chicago Avenue, S.
Minneapolis, MN 55417
612 827-2996
800 53-PACER (MN only)

Mississippi

Association of Developmental
Organizations of Mississippi
332 New Market Drive
Jackson, MS 39209
601 922-3210
800 231-3721

Missouri

Missouri Parents Act-MPACT
1722 West South Glenstone, Suite 125
Springfield, MO 65804
417 882-7434

Missouri Parents Act-MPACT
625 Euclid, #25
St. Louis, MO 63108

Montana

Parents, Let's Unite for Kids (PLUK)
EMC/MCHC
1500 North 30th Street
Billings, MT 59101-0298
406 346-5220

Nebraska

Nebraska Parent Information Training Center
3610 Dodge Street
Omaha, NE 69131
402 346-5220

New Hampshire

Parent Information Center
151A Manchester Street
P.O. Box 1422
Concord, NH 03302
603 224-6299
603 224-4365 (fax)

New Jersey

Statewide Parent Advocacy
Network, Inc. (SPAN)
516 North Avenue, East
Westfield, NJ 07090
201 654-7726

New Mexico

EPICS Project
P.O. Box 788
Bernalillo, NM 87004
505 867-3396

(for Federal Express, UPS:
2000 Camino del Pueblo)

Parents Reaching Out to Help
1127 University N.E.
Albuquerque, NM 87102
505 842-9405

New York

Parent Network Center (PNC)
1443 Main Street
Buffalo, NY 14209
716 885-1004

Advocates for Children
New York City Org./Special Education
24-16 Bridge Plaza S.
Long Island City, NY 11101
718 729-8866

North Carolina

Exceptional Children's Advocacy Council
P.O. Box 16
Davidson, NC 28036
704 892-1321

North Dakota

Pathfinder Services of North Dakota
Arrowhead Shopping Center
16th Street & 2nd Avenue, S.W.
Minot, ND 58701
701 268-3390

Ohio

SOC Information Center
106 Wellington Place, Suite LL
Cincinnati, OH 45219
513 381-2400

Ohio Coalition for the
Education of Handicapped Children
933 High Street, Suite 106
Worthington, OH 43085
614 431-1307

Oklahoma

Parents Reaching Out in Oklahoma Project
1917 South Harvard Avenue
Oklahoma City, OK 73128
405 681-9710
800 PL94-142

Oregon

Oregon COPE Project
999 Locust Street, N.E., #42
Salem, OR 97303
503 373-7477 (Voice/TDD)

Pennsylvania

Parents Union for Public Schools
401 North Broad Street, Suite 916
Philadelphia, PA 19108
215 574-0337

Mentor Parent Program
Salina Road
P.O. Box 718
Senceca, PA 16346
814 676-8615
800 447-1431 (PA only)

Puerto Rico

Associacion De Padres
Pro Biene Star/Ninos Impedidios de Puerto
Rico, Inc.
Box 21301
Rio Pedras, PR 00928
809 763-4665
803 765-0345

Tennessee

ARC/Tennessee
1805 Hayes Street, Suite 100
Nashville, TN 37203
615 327-0294

Texas

PATH
6465 Calder Avenue, Suite 202
Beaumont, TX 77707
409 866-4726

Utah

Utah PIC
2290 East 4500, S., Suite 110
Salt Lake City, UT 84117
801 272-1051
800 468-1160

Vermont

Vermont Information and
Training Network, Vermont ARC
37 Champlain Mill
Winooski, VT 05404
802 655-4016

Virginia

Parent Education Advocacy Training Center
228 South Pitt Street, #300
Alexandria, VA 22314
703 836-2953

Washington

Washington PAVE
6316 South 12th Street
Tacoma, WA 98465
206 565-2266 (Voice/TDD)
800 5-PARENT

PAVE/STOMP
Specialized Training of Military Parents
12208 Pacific Highway, S.W.
Tacoma, WA 98499
206 588-1741

Wisconsin

Parent Education Project
United Cerebral Palsy of Southeast Wisconsin
230 West Wells Street, Suite 502
Milwaukee, WI 53203
414 272-4500

Parent Resource Directory Information Form

If you would like to be included in the database of listings, please complete this form and return it to the National Center for Family-Centered Care at ACCH. If you are already listed in the directory, please use the form to make any necessary changes in your entry.

PLEASE PRINT OR TYPE

1. Name: ____________________

Address: ____________________

City: __________ State/Province: __________ Zip/Postal Code: __________

Telephone (day) __________ (evening) __________

2. Your child's birth date and illness or disability: (If you have more than one child with a chronic illness or disability, please list each child separately.)

Illness or disability:	Birth date: (00/00/00)
__________	__________
__________	__________
__________	__________
__________	__________

3. Where does your child receive most of his or her health care? Please include the name of the hospital, clinic, or other facility and the city and state or province in which it is located.

____

____

Do you have any association with this health care facility other than being a parent of a child who receives treatment there? If you do have another role with this facility, please describe your role or activities.

____

____

4. Many parents find it helpful to join groups or organizations that are concerned with children with special needs and their families, such as parent support groups or disability organizations.

Do you belong to any such groups? Please list as many as you would like to include. If you are an officer or have some other special role in the group(s), please include your title or special activities.

____

____

____

Information Form

5. Do you have any special interests related to improving health care or education for children with special needs? (For example: respite care, financing, early intervention) If so, please describe.

6. Are you or have you been involved in activities to improve health care or education for children with special needs? (For example: Interagency Coordinating Councils for 99-457, parent advisory committees, task forces, designing training programs) If so, please describe.

7. Do you have experience in any of the following areas:

Starting or maintaining a parent or family support group?	Yes ___	No ___
Public speaking?	Yes ___	No ___
Training parents, health care providers, or teachers? *Please circle which one.*	Yes ___	No ___
Promoting legislation?	Yes ___	No ___

8. Do you work outside the home in a health, education, or advocacy field? Yes ___ No ___

If so, what is your job? ______________________________

And where do you work? ______________________________

9. Do you speak a language other than English? If so, please specify.

Please return this form to:

National Center for Family-Centered Care
Association for the Care of Children's Health
7910 Woodmont Avenue, Suite 300
Bethesda, MD 20814

Parent Resource Directory Evaluation Form

1. Does this directory meet a need? ☐ Yes ☐ No

2. In what ways have you used this directory?

3. Will you recommend the use of this directory to others?
If so, to whom? ☐ Parents ☐ Professionals

4. Was the following information useful?

Index of parent names:	☐ Yes	☐ No
Index of disabilities:	☐ Yes	☐ No
Index of special interests:	☐ Yes	☐ No
Index of PTIs:	☐ Yes	☐ No

5. What other kinds of information would be useful?

6. What suggestions do you have for improving this directory?

7. Do you have any suggestions for people and/or organizations to receive this directory?

8. Do you have any general reactions to this directory that you would like to share?

Please return this form to:
National Center for Family-Centered Care
Association for the Care of Children's Health
7910 Woodmont Avenue, Suite 300
Bethesda, MD 20814

ACCH

Association for the Care of Children's Health
7910 Woodmont Avenue, Suite 300, Bethesda, Maryland 20814-3015

Non-Profit Org.
U.S. POSTAGE
PAID
Permit No. 5
Front Royal, VA